Creating a Home and Good Life of My Own

Formal agreements developed by Guelph Services for the Autistic in its role as a housing trust

Elizabeth & Gerald Bloomfield

Person-Centred Homes and Support Networks

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Creating a Home and Good Life of My Own: the GSA experience

Guelph Services for the Autistic (GSA) is a housing trust with a mission of helping adults with autism to live in their own homes with dignity and safety in our communities, supported by family and friends--and with self-directed planning, individualized funding and infrastructure services. Because other families and organizations are interested in the path pioneered by GSA, we have compiled this guide to its various agreements and procedures as possible models.

What factors and strategies lead to best outcomes for adults with ASD?

- A focus on abilities more than on deficits, and strategies based on observations of "what helps?" to balance assessments of "what's wrong?"
- Respect for loving families as the experts on their daughters and sons with ASD and for their uniquely valuable experience and sense of responsibility
- A circle of friends of all ages who care and share time and interests, its core incorporated as an Aroha entity
- Plans and strategies that are individualized and self-directed
- Constructive co-operation among all involved to sustain a whole life that is designed with and by each person and including:
  - -Support to communicate thoughts and choices and to interact with others, in ways that work for each person
  - -Structured, predictable and familiar environments and routines, adapted as needed to suit each person's gifts and choices
  - -Recognition of and help to cope with sensory stresses and transitions
  - -Work and recreational-leisure activities that give a sense of being valued
  - -Opportunities to continue learning
  - -A safe and caring home supported by companions one chooses
  - -Adequate and sensitive healthcare services
  - -Access to all necessary resources and expertise
  - -Advocates to ensure that rights and needs are respected and that existing supports and services are appropriate and adequate.

See inside back cover for more on GSA's publications and other resources.

Creating a Home and Good Life of My Own: the roles of a housing trust

Elizabeth & Gerald Bloomfield
for Guelph Services for the Autistic

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Preface

When we first arrived in Guelph exactly 43 years ago, we had no idea that we would spend the rest of our lives here. Nor that most of our family's energies would be devoted to trying to support people with autism. When our son was diagnosed in mid-1972, we knew little of autism and had no experience relating to people with disabilities. Our son had to live away from home for about half his life, in search of effective programs. But it was often too little, too late for him, especially as he became an adult.

For more than 20 years we tried to improve the general level of autism awareness and services in the hope that life would become better for our son too. In 1996, in circumstances both tragic and hopeful, we decided that there must be better ways for an adult with autism to have a whole life. We shifted our main focus to him, to see if an individualized approach could be effective. We thought and planned and experimented with his active co-operation and encouraged by kind friends in our region and a network of disability advocates. In 1997-8 GSA took up the challenges of becoming a housing trust and sheltering various innovative supports. Our son was able to tell everyone what elements should be in his good life. We have taken our lead from him, with remarkable success for someone with complex symptoms and high support needs.

As our son's life improved, he has wanted to share what works for him with other adults who could benefit and whose families are interested. We offer this manual as a record of strategies that have been thought through and tested to realize and sustain whole lives. We honour our son for his generous spirit and perseverance, and we thank all who have been our friends and allies.

Elizabeth & Gerald Bloomfield
Guelph, Ontario, Canada
3 January 2012

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Note

The authors and GSA want the information in this publication
to be useful for and with persons who are vulnerable
because of their differences and special needs.

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1 Introduction to GSA's Role

Guelph Services for the Autistic (GSA) has functioned as a housing trust since 1997. Its mission and main focus is to help adults with high support needs because of the complex challenges of autism to have their own homes and to be included with respect in our communities. GSA has pioneered ways of encouraging self-advocacy and coordinating private and public resources and the efforts of families and friends. Elements of a good whole life include reliable self-expression and self-directed planning, direct individualized funding, and a sustainable continuum of support. Adults assisted in this way to have their own homes are GSA's "active members", other supporting friends being "associate members". Because other families and organizations are interested in following the path pioneered by GSA, we have compiled this guide to its various agreements and procedures as possible models.

Why and how did GSA develop into a housing trust?

From first incorporating in 1980, GSA's founding members were looking ahead. Their sons and daughters, then in their early teens, had quite severe symptoms of autism. Autism was defined much more narrowly than it would be from the late 1990s, and numbers were small. There were no local services and even special education was not yet mandatory. Our young people had to live away

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from their homes or commute long distances to get any Government-funded programs designed for their needs.

As a voluntary advocacy and support group, GSA worked through several generations of proposals for adolescent and adult residential services. We spoke up for persons with autism and organized meetings and proposals on innovative ways of supporting them. From 1991, we collaborated with our regional neighbours in the incorporation of Waterloo-Wellington Autism Services (WWAS). Together we planned for three successive pilot projects over the next four years—a pair of group homes, development of autism information and resources, and an experiment in "enhanced supported employment". Some Government resources were obtained for the second and third of these, but funding dried up at the end of 1995.

A combination of factors in the mid-1990s influenced GSA's sense of purpose. The Ontario Government was closing the institutions or "facilities" that had housed about 50,000 people with developmental disabilities since 1870. Incentive funding was offered to agencies to accept people being "re-patriated" to their home communities, usually to accommodation in group homes. In the same period, governments at all levels were cutting off social housing funds that had supported some earlier innovative projects.

A high proportion of the last to leave the institutions were probably adults with the symptoms of autism who had not been formally diagnosed. We were very aware that our friends with autism did not fit comfortably into institutions or group homes. They did not thrive in group living environments. Their special needs were inadequately understood and the staff seemed to treat them as challenging and barely manageable only with physical or chemical restraints. Their families were too often excluded from their lives. We felt there had to be a

better way, in which vulnerable persons would be supported to express their thoughts and choices and their families would be respected and included.

But there were also signs of hope. People with autism severe enough to prevent them from using their voices, when given the opportunity to use Alternative and Augmentative Communication (AAC), were beginning to show that they could both understand what was going on around them and express their thoughts and feelings reliably.

Progressive ideas of tailoring supports to the individual person and building community resources to include them were gaining ground. Individualized funding, pioneered in British Columbia and later adopted as official government policy in Alberta, was being discussed in Ontario. Workshops on these new approaches were offered by Homes for Adults with Autism and Pervasive Developmental Disorders (HAADD) in Toronto in 1996. With others who advocated alternatives to the traditional services and more choice for persons with disabilities, we were associated in early meetings of the Individualized Funding Coalition for Ontario (IFCO) and have continued to be connected.

GSA's re-orientation in 1997 was focused by the urgent needs of one person. "Anthony" (let us call him that) lived with quite severe symptoms of autism and had endured some very unhappy experiences of group living. His parents were his only family in North America. The tragedy of his twin sister's accidental death concentrated the minds of his parents and friends to devote resources and energies to helping him to build a new life of quality and respect. Though he could not speak with his voice, Anthony was able to express himself with Supported Typing (a form of Augmentative and Alternative Communication) to ask consistently for "a home of my own" in his home city, among other key elements of a good whole life.

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Pioneering models of "one's own home" for a person with a significant disability were known to us. We were inspired by the individual home and life developed around Catherine Schaefer by her family in Winnipeg in the 1980s. A little later, the NABORS project in Toronto (Neighbours Allied for Better Opportunities in Residential Support) aimed to build community and achieve inclusion for people with disabilities by designing apartments for them in social housing projects that were intended for other tenants as well. In both these examples, the entities responsible for personal supports were different from those that owned and maintained the homes. This is considered a safeguard that the interests of a vulnerable person come first and are not subordinated to the interests of the agency.

Catherine Schaefer was supported practically and emotionally in her large home by several lifesharing companions. We liked the lifesharing idea very much, as a natural way of encouraging social relationships and building intentional community around the person. In our mind, the focus person would choose the people to share her home and support her. If difficulties could not be resolved, the support people were the ones who had to move on. The focus person stayed in her home. To make this work sustainably into the future, it was necessary to have the legal powers of a housing trust that was unencumbered by other responsibilities such as being an employer. To keep the focus on the person and her rights of decision-making, it helped when families were substantial partners in the enterprise—as funders of capital and other costs for the home, and also involved in whatever ways were needed to establish the new whole life.

So, for these reasons, GSA in late 1997 took up the new role of housing trust, to enable individual persons with handicapping conditions to own their own homes with the best possible support for everyday living and as a basis for a lifelong

continuum of support. Anthony became GSA's willing pioneer, his abilities and needs prompting the fullest development of the GSA model. Responding to his situation, GSA and its lawyers immediately developed GSA's own revised bylaws to work as a housing trust (Appendix 3). Anthony's parents bought a spacious and well situated property to be his home and made a family funding agreement with GSA (Appendix 5). GSA and Anthony signed the occupancy agreement (Appendix 6), spelling out everyone's responsibilities in legal and plain language. The lifesharing agreement (Appendix 7) and procedures were drafted.

All so far had been achieved without official encouragement or help. During 1998, we had to work out ways for Anthony to receive the individualized disability support funding for which he was eligible, if he was not being sheltered by a traditional agency. For about 18 months, Anthony and his family were in limbo, his family paying for his home and a large part of his support costs. The ideas of a home of one's own and lifesharing were regarded as too innovative and individualized for the traditional agencies or service system.

Thanks to networks among progressive advocates in Ontario during 1998, we reached Malcolm Jeffreys of Windsor Community Living Support Services who was then encouraging person-directed approaches for people and families in his jurisdiction as well as helping to found what would become the (unencumbered) Windsor-Essex Brokerage for Personal Supports (WEBPS). Malcolm was so glad to see a person, family, circle of friends and housing trust taking on innovative roles, that he offered his agency's help as transfer payment agency. A Personal Support Agreement and statement of Continuous Quality Improvement were drafted and signed by Anthony himself, his parents, and by representatives of GSA and the Transfer Payment Agency (Appendix 8).

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Towards Better Lives and More Secure Futures for Adults with Autism

Advice to younger families with autistic children: Start early, even from childhood, and keep evolving these interrelated strategies.
(GSA presentations from 2001)

1. Encourage self-expression and choices by whatever means.
See the humanity, abilities and potential in your sons or daughters, however severely challenged. "Listen", especially when they do not speak with their voices, to understand their point of view and priorities. Observe and record what strategies work best.

2. Find and keep friends of various personalities, ages and abilities, who get to know the person very well and can support and continue the parents' roles. Friends can support one another as well as the person when organized as a Circle or Personal Support Network. Vulnerable adults need friends and allies in addition to family and those who are paid to be in their lives.

3. Plan with the person.
Planning tools such as those developed by Inclusion, such as PATH (Planning Alternative Tomorrows with Hope), MAPS and CIRCLES, help in working through transitions, envisioning a good life, and devising strategies to attain it.

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4. Be creative and flexible in setting up key parts of the person's plan for a good life. Don't be limited by the traditional service system. Consider what's really needed and find ways to make it happen. Have a clear understanding of person's highest priorities and general goals. But also be open to the unexpected opportunities, even serendipity.

5. Consider the best kind of living situation for each person. People need choices. Someone with hypersensitivities may need her/his own home, supported in the ways she/he needs and shared with companions she/he chooses. Guelph Services for the Autistic (GSA) is pioneering an individualized model of homeownership that includes choice and self-direction by the person, long-term capital investment by the family, support circles, and recruitment and matching of lifesharers and volunteers.

6. Daily activities must be real and fulfilling and include continued learning, healthful exercise, and contributions to the community. Each person should have a way of life that is uniquely suited to needs and interests, and should be able to comment and make requests and suggestions. Support workers should be chosen by the focus person and carry out their wishes.

7. A good life must be sustained, beyond the lives of parents. An innovative mechanism is the Aroha, an incorporated entity of personal support (aka "self directed support corporation" or "microboard"). An Aroha can give trusted friends of the person and parents the legal powers to strengthen and continue family efforts. An Aroha can own property, and receive and manage resources to match person's needs and wishes.

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Thus, within one year of GSA's first re-orientation as a housing trust, four of the six agreements in this manual had been drafted and put into effect. As we now see, the other two agreements should come first in an ideal process of developing a good whole life in one's own home. GSA was constrained by Anthony's urgent need for his own home, and he was already able to express his thoughts and needs and had a strong circle of friends.

During the following 2-3 years, for others besides Anthony, that we realized that full development of a good whole life depended on two other elements that should come earlier in the process:

- Reliable communication by the person in expressing thoughts, feelings and dreams, as the basis for a formal supported decision-making agreement (Chapter 2 and Appendix 1)
- Incorporation of an Aroha entity as the core of a person's circle of friends and support network (Chapter 3 and Appendix 2) and a key agent in sustaining a good life and a partner in all the other agreements (Appendices 2, 4, 6, 7 and 8).

These two agreements were drafted and put in place to support Anthony's good whole life by early 2002. The various entities and agreements are discussed and presented in the chapters and appendices of this book.

What are the essential principles of supporting a vulnerable person in a good whole life?

1. *The person is centrally involved in planning and realizing her or his whole life.*

We must listen deeply to each person in whatever mode of communication works for them. This communication must be two-way. We don't just expect

them to communicate our way and assume they have no intelligence or feelings if they cannot speak with their voices. We don't assume our vulnerable friends cannot understand our language. As friends and supporters, we also try to learn the ways they do express themselves. We have learned that "presumption of competence is the least dangerous assumption". We try to open our minds to the possibility that they are smarter than we may have assumed. When we shift our assumptions, we are continually amazed by their insights and wisdom.

We knew intuitively as loving family members that this is a first principle of support. But our understanding has been deepened since one of GSA's active members took the lead in forming a communication support group in 2004. All vulnerable adults should be encouraged and supported to express themselves. This is a basic human right and also a wise and sensible strategy to encourage coping skills and reduce frustration. We would urge all families of children and teenagers with communication challenges to help them find the most reliable ways of expressing their thoughts and feelings. These can be the basis for supported decision-making and self-directed planning, using whatever two-way modes of communication work for the person. We support the mantra of various self-advocates' groups: "Nothing about me without me!"

These ideas are explored further in Chapter 2, "Listening to the Person", with a model Supported Decision-making Agreement in Appendix 1. But the person's voice and choices are involved in all the agreements.

2. *One's own home is an essential anchor of a good whole life*

For any homeowner, home is a haven, a place to relax and be oneself, a base for activities and interests, a symbol of control over one's life, and a place in which to host friends and express one's individuality. It is also often our biggest investment and the basis of financial security as we get older.

If a home is important to those of us without special needs or complex handicapping conditions, how much more is it vital for people who may have much narrower lives because of a developmental or other disability? A home can be customized for a person with the hypersensitivities that make group living so hard for some—using adaptive and assistive technologies of various kinds. If a home is equity for non-disabled people as they age, how much more should a person who is vulnerable be able to have a secure home?

People who live with complex challenges can grow into pride of ownership, a sense of responsibility, and the joys of being host. Support people are chosen by the homeowner and enter the home respectfully as they would the home of a neurotypical person. The activities of the home can revolve around the homeowner who may not want to go out to a day program every weekday. Having one's own home also allows the person to invite lifesharers to share the home and provide live-in support as an intentional household community.

Home ownership is basic to all parts of the GSA model but explored particularly in Chapters 4, 5, 6, 7, and 8 and the model agreements in Appendices 3, 4, 5, 6, 7 and 8.

3. *Families (widely defined) are respected and involved for the friends and community connections they make for the person.*

Instead of being sidelined as can happen when an agency takes over, parents and siblings should remain centrally involved as advocates and interpreters of the person to others. They can also take the initiative, with their son or daughter, to plan and realize a good whole life that is sustainable.

Parents or other family members can choose to invest in their son or daughter's home and good life, now and into the future. A family could contribute all or part of the capital and maintenance costs of the home, with GSA registering the family contribution as a mortgage on the property. This investment is not interest-bearing but could be repayable to the lenders or their estate under certain conditions--if the person dies or wants to move away, or if GSA cannot continue to protect the person's occupancy for any reason. Family members and friends may also make tax-creditable donations to help GSA and serve as directors of the incorporated Aroha entity or the GSA Board.

We encourage families to share the challenges and satisfactions of supporting a son or daughter who is vulnerable because of severe disabilities. But we know it can be hard to let go. Parents have deep knowledge and long experience in helping their family member to cope: their understanding of the ten thousand individual details is vital for those who may eventually succeed them. Sadly, some families living with autism have sensed or imagined negative attitudes from extended family or neighbours and find it hard to believe that anyone else could want to help. Some agencies may seem to drive a wedge between adult clients in group homes and their families.

For aging parents of people with complex disabilities, it can seem easier, even more fulfilling, to continue coping and sharing life with their disabled son or daughter. They may have had to rescue their son or daughter from a failed group home or other kind of living arrangement, and are very reluctant to take another risk, fearing that they might not have the energy to rescue their family member again. Parents may just carry on and make very little provision for a future when they will become ill or die.

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We understand and sympathize with these fears by families. We honour families who have continued their loving care of their disabled sons and daughters to the end of their lives. Their memories and records are invaluable. Many adults with autism also seem most comfortable continuing in their family homes with their much loved parents and the familiar routines and culture. But we encourage families to plan for a combination of their continued involvement with encouragement of the person's own voice, interactions with more people, and sustainability for the longer term.

Rearing and advocating a child with disabilities, especially if these are severe and complex, gives good parents a great deal of knowledge about what does and does not work and the authority to speak and advocate for their family member. But an assertive parent might prevent their son or daughter's real voice from being heard. A wise parent will encourage all possible and positive ways for their son or daughter to express their own voice—starting at a young age.

Every adult with a severe disability needs and deserves relationships with others besides their parents, just as non-disabled people do. They need scope to grow and develop their own choices as well as the experience of relating to different kinds of people. This can begin from quite an early age with a circle of friends. The more formal Aroha entity, in concept and practice, brings together the family and trusted friends who can learn to supplement and eventually succeed the parents and thus sustain the person's good whole life. Members of the extended family can also be invited to be part of the circle of friends.

Families are a key part of the GSA model, from their confidence in and love for their son or daughter to their willingness to provide funds for the person's home and to share their unique knowledge of the person with all the friends and entities that will make a good whole life sustainable.

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4. *Each person has a circle of support, also incorporated as an Aroha entity*

Friends are the greatest resource for a vulnerable person, building community and inclusion by sharing parts of their lives and interests, and connecting with others who can offer friendship as well as opportunities for the person to contribute their gifts. Friends can help to find potential support workers and lifesharers. Everyone who is vulnerable should have a circle of friends of which the core can be formally incorporated as an Aroha.

Adults with autism, contrary to stereotypes about ASD, know that friends are their most important allies. Friends accept and like you as you are. Friends understand and help with the ups and downs of your life. Autistic adults may particularly want friends who are neurotypical (i.e., not autistic) because they may have been limited to the company of only disabled people in segregated settings. Above all, they want to have choice in who will be their friends, support workers and lifesharers.

GSA strongly recommends that core members of the circle of friends incorporate as an Aroha entity of personal support in order to complement and eventually succeed the roles of parents. An Aroha is equivalent to the entities known as microboards or self-directed support corporations elsewhere.

For the constitution and functions of an Aroha, see particularly Chapters 3 and 5 and Appendices 2 and 4. But the Aroha is a key partner in all the agreements and vital to making them work.

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5. ***Individualized funding, self-directed planning and independent facilitation are essential.***

The more complex a person's needs, the more individualized the supports should be. Everyone is different—in their dreams, gifts and needs—and people with autism may have little in common apart from their diagnosis. Vulnerable people should not be squeezed into moulds, for administrative or financial convenience. Plans should be individualized and evolving, indicative and flexible rather than binding blueprints. We know that a good whole life must have certain qualities, but we cannot foretell exactly how we will get there. There should be room for the serendipity factor, when some wonderful opportunity may open up unexpectedly. A person's abilities and needs may change, sometimes towards needing less support. But sometimes, unexpected health issues may need a review and expansion of the essential supports.

People with complex needs could benefit from the services of independent facilitation and planning of personal supports. This kind of help is now being recognized by the Ontario Ministry of Community and Social Services.

For GSA, it is wise to have a balanced division of responsibilities among several kinds of entities that are linked by their commitment to the individual person. As a housing trust, GSA's function is to hold and administer property in trust for a person's lifetime, subject to any necessary personal and financial safeguards. An Aroha has powers to support the person with all necessary funds and in contracts and agreements with any people or organizations that provide service. An Aroha's directors also help the person with supported decision-making in the three areas of financial/business matters, health, daily living and personal care. Planning, facilitation and brokerage of supports should be independent of any service-providing organizations. Every entity and person concerned signs their

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assent to the Personal Support Agreement and protocol for continuous quality improvement to ensure that a person's plan is well co-ordinated to achieve what he wants.

6. *Keeping connected with others who are thinking creatively and pioneering better ways of supporting people who are vulnerable because of disability*

GSA itself has taken a lead in some of this, offering information and connections among people interested in alternative options in housing, communication and social support. Since 2000 GSA has also sheltered OAARSN: the Ontario Adult Autism Research & Support Network at http://www.ont-autism.uoguelph.ca and the Listserv networks on Adult Autism Issues and Creative Supports for Vulnerable Citizens.

In November 2001, we organized the Guelph Focus on Microboards workshop, which was led by David and Fay Wetherow of British Columbia and attended by 60 from across Ontario. GSA's Autism Support Project: Information, Resources, Empowerment (ASPIRE) from 2002 to 2005, among other things encouraged vulnerable persons with their families in our larger region to plan, often using the PATH approach (Planning Alternative Tomorrows with Hope).

In April 2005, GSA offered a conference and workshops in Guelph to feature new forms of Creative Supports for Vulnerable Citizens, and published proceedings of this event and a summary videotape. As one result GSA has been one partner with other community organizations in efforts to make independent facilitation and planning available for adults with developmental disabilities in our Wellington-Dufferin region. Since 2005, GSA has also sheltered the communication and self-advocacy support group, Bridges-Over-Barriers.

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Ten Steps to Realize a Personalized Plan

Step 1: Begin Self-determination

I decide to begin the process of self-determination, encouraged by the people closest to me. We know that alternatives to traditional group services and programs may give me the best support with what I want—how I spend my time, with whom I live, and how I express my needs and priorities. This process may also be a bit scary, because we will not be able to copy or fit into familiar programs and we may have to explore new ways.

Step 2: Form Support/Cluster Network

I form my cluster, circle or network of family members, friends (of various ages) and professionals, as the basis for an Aroha entity of personal support. I know that friends who spend time with me, understand what is most important for me, and care about and speak up for me are the best guarantee of my quality of life, now and in the future.

Step 3: Set Up Ways to Understand and Make Choices

My support group and I set up ways for me to understand and make choices and for others in my life to understand me—which may mean "alternative and augmentative communication" systems and support people who know how to validate what I say. I use my way of communicating in all these steps.

Step 4: Make Personalized Plan Using MAPS and PATH

My support group and I draw up my personalized plan using tools like MAPS and PATH (Planning Alternative Tomorrows with Hope) of Inclusion.com. We dream of where and what I want to be in say 5 years and brainstorm about ways to get there, taking stock of my gifts, abilities and challenges.

Step 5: Assess Ways and Means

We assess ways and means to realize and sustain my plan. We look at all essential costs and any available resources (including informal or non-monetary ones). To start with, we ensure that I have applied for disability

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pension and other allowances for which I may be eligible. But we also look creatively at all other possible resources in my community.

Step 6: Weigh Up Options and Decide Best Combination

We have to balance hoping and believing that things will work out for the best with knowing that Murphy's Law often operates and that we must be prepared for the hard days and gaps in support. It helps to have some level-headed folk in my support group who are good at scheduling and accounting. Above all, we ask this question about every plan: "Is it good for me?"

Step 7: Choose Broker to Negotiate Supports and Funding

We find a broker who will work for my interests in negotiating supports and resources so I can live safely and have hope and quality of life. I need a way to receive and administer funds that is right for me. Agencies involved with my plan must share its values and priorities. Support staff must be people I can trust and who believe in my plan. Resources to realize my plan must be flexible and portable. A broker might be involved in steps 5 through 10.

Step 8: Choose Place to Live

We make a list of the qualities that I need in my own home; we look for places that match my wish list and make the best choice. My family and housing trust work out the business side and my Aroha and I think about and decide what supports I will need to live in my home.

Step 9: Set Up Quality of Life

My Aroha and I plan and set up a satisfying way of life, including continued learning, real work, exercise, recreation and friends, with needed supports.

Step 10: Set Up Ways to Co-Ordinate Everything

My Aroha and I set up ways of co-ordinating all parts of my plan and way of life, so they work together smoothly into the future, even when other things and people may change. We compose and everyone signs Personal Support Agreement and statement of Continuous Quality Improvement. If we have chosen well at all the other steps, we have the best chance of success.

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Ten Steps to Realize a Personalized Plan, narrated in the first person on the preceding pages, is also shown as a poster on the back cover. It was first devised for GSA in 1999 and updated in 2005. See also the more detailed graphic version on the OAARSN website at http://www.uoguelph.ca/oaar/STRATEGIES8.shtml

Who could find the GSA model useful?

This summary of GSA's experience is not a blueprint for all. We hope that it will spark hope and ideas of possibilities, with the knowledge that these strategies have all worked in Ontario. Persons with a disability, parents, siblings and extended family, friends, neighbours, community, agencies and society as a whole can all benefit from this approach.

The full GSA model is appropriate when a person (with family and friends) wants to plan a self-directed life for the long term, and there are family funds for the capital costs of the home and individualized funding for disability supports, as well as good dedicated friends willing to be Aroha directors.

In the idealized sequence:

- The person is encouraged to express himself about all his wants and dreams, including the importance of a home of his own in his life; and everyone in his circle makes a commitment to listen and to support in whatever ways are needed. This process may be helped by an independent facilitator.
- Family and friends organize themselves into a larger circle of friends, with a core group able to incorporate as an Aroha entity.
- Parents (or other family members) plan whatever financial resources they can contribute to the capital costs of the home.

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- The person, with help from the Aroha and perhaps an independent broker or facilitator, seeks direct individualized funding and negotiates agreements with any community organization or agencies needed for personal supports or infrastructure services.
- Relevant legal agreements are made and signed among GSA and all parties.
- Friends seek good people to be interested in lifesharing or as support workers or tutors; the person and Aroha conduct searching interviews, and agreements are made with whoever proves suitable.

At first glance, the GSA model might seem very complicated and rather formal. All those agreements! Parents preoccupied with coping from day to day might say "Let's wait till we die. Something might turn up before then. Couldn't we leave all the responsibility to the siblings? Or what about the local agency whose ED seems sympathetic?" But if you care for your son or daughter as a person and want them to have a good whole life, you should consider something like GSA's model that combines listening to the person with sustainability of one's home, close personal relationships, and a mechanism for support funding. The housing trust's responsibility for the person's longterm occupancy of the home is balanced by the Aroha focus on the person's whole good life.

The GSA model is not for the faint-hearted or for tentative dabbling. But a deferred version of the full GSA model could suit some persons and families. Parents could continue to live with their son/daughter but intend to deed the family home to GSA when they become too old or ill to provide active support. GSA could make a conditional agreement to administer the home and to respect the person's decision-making, on condition that an Aroha entity is already involved in relationships and responsibilities. The family might gradually make

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plans that are consistent with GSA's role. Once the occupancy agreement becomes effective, its features would be as in GSA's full model.

With suitable amendments to GSA's key agreements, two or three adults with their family groups might combine to finance a home. Sharing a property might make the capital and support costs more manageable. GSA would need to be sure that each person has chosen this path and can reliably communicate their dreams, needs and choices. Each person would need his or her own Aroha entity to ensure that his or her good life is self-directed and supported by caring friends. The two or three family and Aroha groups would have to know one another well and share the same values and respect for each adult sharing the home. There would have to be contingency plans to cover future possible changes—so that if one person and family withdrew for any reason the home would still be sustainable for the other one or two occupants. A shared project might best provide for the needs of two or three individuals in the same building if it were subdivided or remodeled into two or three private living units with some shared community spaces. There might, for example, be separate suites with bed-sitting room and ensuite bathroom as well as a large shared kitchen, living room and recreational space with a small office.

With a combination of social housing and family funds, GSA might sponsor and co-ordinate a co-op or cohousing community of 4, 6, 8 or more individual apartment units sharing a community centre—which might be designed for the purpose. The GSA set of agreements would be used to support each person taking part in such a project. This version would also require more co-ordination and mediation among the various partners, as well as core funding for the whole project to supplement any contributions from family partners.

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When GSA began its role as a housing trust, there was no official recognition of a family initiating and being a partner in an individualized life and home for an adult with complex needs who could have real choices. By mid-2007, however, the Ontario Ministry of Community and Social Services was inviting proposals for the Individualized Residential Model Initiative (IRMI). For a limited period, adults who met certain criteria with their families and agencies could submit proposals for "individually tailored ...housing options" that also recognized the "ability of families to provide supports". More than 60 projects were approved to receive Government funds for support staff and 89 people were said by early 2009 to be living in an IRM thanks to this funding. The Ministry hosted forums in April 2009 to pool the reactions and recommendations of agencies and family members who had experience in working together in individualized residential projects.

Government funding for such projects has not yet been repeated though family groups are encouraged to plan individualized housing for their sons and daughters, using whatever resources they can find to be ready for future possible funding. The GSA model would be valuable in this process and help with what were considered weaknesses in IRM pilot projects—especially for a person's self-expression, the roles of Aroha and housing trust in sustaining a self-directed life and maintaining a person's home into the future beyond the lives of parents, and the need for more independence from direct service agencies.

Various of GSA's model agreements could be used alone, or could inspire analogous agreements. A Supported Decision-making Agreement (Appendix 1) and an Aroha entity and agreement (Appendices 2 and 4) are recommended for everyone who is vulnerable. The person-centred and self-directed qualities of the Occupancy Agreement (Appendix 6) and Personal Support Agreement (Appendix 8) are good models for other agreements.

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2 Listening to the Person

How do we ensure that the real wishes and values of adults with complex disabilities are respected? Adults with autism may not communicate in ways that are easily understood, so others may stop "listening" and doubt the person's intelligence. While we may speak up for self-determination in theory and want to respect the tastes and preferences of each person with a disability, in practice or by default we tend to err on the side of safety and protection. Some parents may seem over-protective, offering very few choices. Some supporters may be so keen on choice that they would remove all safeguards, so that a vulnerable person may be open to exploitation.

GSA upholds the communication rights and abilities of its members, both as a matter of social justice and as a vital way of ensuring that their good whole lives are self-directed. The Bridges-Over-Barriers self-advocacy group, sheltered by GSA, is showing the way.

It is now more than 60 years since the United Nations passed the Universal Declaration of Human Rights, asserting in its first clauses: "All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood." But with so much that needed rebuilding in the world then, the rights of people with disabilities were overlooked. In 1975, the UN General Assembly approved the

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Declaration on the Rights of Disabled Persons, which states that all persons with disabilities are entitled to the rights stipulated in the Universal Declaration of Human Rights. At the time this made little or no difference in the lives of people with severe disabilities.

In December 2006 the Convention on the Rights of Persons with Disabilities was adopted by the UN General Assembly. According to ENABLE, the UN agency charged with administering disability issues, the Convention took "to a new height the movement from viewing persons with disabilities as 'objects' of charity, medical treatment and social protection towards viewing persons with disabilities as 'subjects' with rights, who are capable of claiming those rights and making decisions for their lives based on their free and informed consent as well as being active members of society....[The Convention] reaffirms that all persons with all types of disabilities must enjoy all human rights and fundamental freedoms. It clarifies and qualifies how all categories of rights apply to persons with disabilities and identifies areas where adaptations have to be made for persons with disabilities to effectively exercise their rights and areas where their rights have been violated, and where protection of rights must be reinforced. [In the Convention] 'Communication' includes languages, display of text, Braille, tactile communication, large print, accessible multimedia as well as written, audio, plain-language, human-reader and augmentative and alternative modes, means and formats of communication, including accessible information and communication technology..."

Meanwhile a few organizations in developed countries had made declarations in favour of the communication rights of people with disabilities such as The Communication Bill of Rights of the American Speech-Language and Hearing Association in 1992, composed by the National Joint Committee for the

Communicative Needs of Persons with Severe Disabilities as part of "Guidelines for meeting the communication needs of persons with severe disabilities".

COMMUNICATION RIGHTS (summarized)

All people with a disability of any extent or severity have a basic right to affect, through communication, the conditions of their existence. All people have the following specific communication rights in their daily interactions, to:

- *request desired objects, actions, events and people*
- *refuse undesired objects, actions, or events*
- *express personal preferences and feelings*
- *be offered choices and alternatives*
- *reject offered choices*
- *request and receive another person's attention and interaction*
- *ask for and receive information about changes in routine and environment*
- *receive intervention to improve communication skills*
- *receive a response to any communication, whether or not the responder can fulfill the request*
- *have access to AAC (augmentative and alternative communication) and other AT (assistive technology) services and devices at all times*
- *have AAC and other AT devices that function properly at all times*
- *be in environments that promote one's communication as a full partner with other people, including peers*
- *be spoken to with respect and courtesy*
- *be spoken to directly and not be spoken for or talked about in the third person while present*
- *have clear, meaningful and culturally and linguistically appropriate communications*

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Communication is a basic human right. Humanity and compassion should move us to do our best to "listen" to someone who often lives in pain and discomfort and cannot speak with his voice. At the very least, it is also rational and prudent to help someone to express himself and be understood when the alternative may be extremely frustrated behaviour that is inconvenient or even dangerous.

People who live with the complex disabilities of severe autism are in a triple bind. Their severe neurological challenges mean that many cannot use their voices to speak reliably. Their muteness and behaviour may be misunderstood as lack of intelligence or feeling for others. Some adults with autism were fortunate to be introduced from 1991 to a form of AAC which we now call Supported Typing (S-T). For those who were able to persevere, "typing to talk" has been a liberating experience. Sadly, however, a reaction based on misunderstanding of how S-T works has cut off people who might benefit from using this mode of communication for nearly 20 years. Adults who asserted their rights and abilities to express themselves in alternative ways have had to struggle against negative assumptions by others, including those in authority. It often seems that the bar has been set higher for adults with severe autism than for other people.

We knew intuitively and by close observation of our friends with autism that support for self-expression and two-way communication is a basic principle. But our understanding has been deepened since one of GSA's active members took the lead in forming a communication support group in 2004. Other adults whose movement differences do not let them speak reliably with their voices meet regularly in Guelph for conversations about their lives, using the form of AAC known as Supported Typing. Now sheltered by GSA, the Bridges-Over-Barriers members co-operated to produce and publish a DVD and book in 2010. They share their "struggles and strategies" and learn from one another about their rights and about choices they may make to improve their lives.

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Some Questions Discussed by Bridges members, 2004-2009

What strengths can I bring to a community of friends?
How do we find good friends?
Who are our friends?
What qualities do I want in a friend?
Do we need different types of friends?
How have I made friends in the past?
Where might I look for new friends?
How do you tell people you want to be friends?

What is it like, not being able to rely on our voices?
What about when we know what to do, but can't get our body and muscles to co-operate?
How do we get people's attention to help us when we are stuck?
What helps us to move when we feel stuck?
Does everyone have times of being "hyper", restless, always in motion, unable to stop our movements?
What is the connection between being unable to move our bodies sometimes and not being able to speak with our voices?
How can other people recognize our difficulties and provide the assistance we need?
What happens if someone tried to stop us when we are hyper?

We are hypersensitive to touch—how is this important in knowing how to support us?
How are we aware of other people?
Why do we feel everything so intensely?

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How do I hear and feel sounds, rhythm and music—in my heart and emotions?
How do sounds, rhythm and music affect our ability to express ourselves?

Why do other people not realize we are smart?
What makes my life worthwhile?
What does security mean?
What do I need in my life to feel a sense of security?
What are the qualities of families that make us feel secure?

How does communication figure in my sense of security?
What difference does Supported Typing make?

How to have more choice and control in directing our own lives?
What things do I want people to know so they can support me well?
How well included am I in making life plans?
How can we cope when familiar friends and support workers leave us?
How could direct Individualized Funding help me?

Clearly, Bridges-Over-Barriers means a great deal to its members. One of them reflects:

> *I think that being able to talk to others who use ST helps me talk more about how I feel about myself. I need to talk about this with people who understand why ST is important to each of us and how we need to mentor and encourage each other to keep trying new things even when it's uncomfortable.*

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I feel like my Bridges friends are my family too. It is important to feel like I belong to something and someone. I always learn something interesting from the meetings. I think that everyone tries very hard to be caring and respectful of each other--that is what friends do right.

I can express how I feel and it's okay. I am full of ideas that people want to hear about and I feel good about this. Now I am understood, not misunderstood, and people ask me what I need, not guess. I feel I belong now. When I didn't use ST I was misunderstood.

I think that through Bridges ST has gotten the attention of others and they are listening and understanding me better because I am not the only person who uses ST. I am one of many smart, intelligent, interesting people who are sharing their ideas and life with others. It is important that friends, supporters and allies keep listening and asking so they can understand.

We friends and family members who have been privileged to observe Bridges conversations have learned so much during the past eight years. We are amazed by the fluency and insight of the communicators and their patience, empathy and generosity of spirit. We know that as a result of their conversations various Bridges members have taken the initiative to improve their lives.

The Bridges experience also teaches us the vital importance of deep listening. Bridges members together composed this definition of the meanings of hearing, listening and paying attention for themselves. Their words have meaning for all of us who would be their friends and supporters:

Hearing is with your ears only, but you may not understand.
Listening is with your heart and taking in the meaning.
Paying attention is using your mind to focus on the person who is talking...

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Why/for whom are we making the Bridges movie and book?

- Everyone should know that our lives and thoughts are normal.
- People who don't think we have thoughts of our own, who don't believe in us, to prove we can talk and that we are smart.
- Sceptical and negative thinkers who work with autistic people.
- People who want to learn to use S-T with us, new supporters as well as our parents.
- Our support circles, so they renew their faith in us and try harder to help us improve our lives.
- Bridges members who live far away to help them make new friends.
- We are affected by autism and we need support to talk and to live our everyday life. We want to show people who don't understand that we can talk by typing and listening to each other, and that we are smart. People should know that we are doing the talking--not with our voices but with Supported Typing.
- We have thoughts of our own. I am a good man, smart and can communicate well. I am strong at listening, understanding and being myself. I can do things. I do not like to be talked down to.
- People should know how hard we have to struggle to behave appropriately, as well as about our joy in communicating with others. The world should wake up and accept us as we are. We want to be recognized as intelligent, sensitive and spiritual people who love God and others. We want to be accepted in a faith community where we can be involved and needed. People with autism and disabilities are more in tune with spiritual things because their world is silent and their hearts are open. We need to be allowed to make our own choices and to try new things. People need lifelong education and recreational opportunities.

Record of discussion by Bridges members, printed in *Bridges-Over-Barriers: In Our Own Words* (2010), p. 102.

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The Bridges experience also provides lessons for how adults with severe autism can effectively be helped to share their thoughts with people who may be able to help them realize their goals. We need to make accommodations and adapt environments and meeting formats to help communicators express their real and full intentions. People with complex movement disorders and sensitivities to all stimuli, and who have to tap out their words slowly letter by letter, need everyone present to be quiet, patient and supportive. Large gatherings with lots of social chatter may be overwhelming. They do not like to be taken by surprise and certainly not to be put on the spot by requests for simple "Yes or No" answers.

Circle meetings, good as they may be for some people with disabilities, may not be the best way for adults with complex autism to express their thoughts, needs and dreams. Yet circle meetings are valued and accepted ways for a person's non-autistic friends to get together. For our Bridges and GSA friends, a several-stage process may be most effective. A communicator can compose thoughts in advance about his priorities and the areas in which he need his friends' help. These messages, with the person's consent, can be shared around the circle of friends and may prompt questions and suggestions, with some email conversations. The person can be well prepared for a larger event by composing a social story with the agenda. At the meeting itself, the person may choose just to listen, and then to comment later. After the meeting it is good to have debriefing conversations using Supported Typing.

A Supported Decision-making Agreement is recommended to ensure that adults with complex challenges such as autism become "the authors of their own lives." Such an agreement should be set up while parents are still alive to support the process. Institutional and legal alternatives (such as in funding for programs and

services; regulations and policy; and legal guardianship) all have weaknesses and are based on false assumptions.

Almost everyone—with or without a disability--has some kind of support in making decisions. Most of us make decisions in collaboration with others. We ask advice from experts in various fields and may trust their recommendations even when we do not fully understand the financial, legal or medical intricacies. We often discuss choices with partners, spouses or best friends. The only real protection for our sons and daughters with a disability is the quality of the committed relationships they have. In the GSA model, these relationships are strengthened by the legal powers of the Aroha entity (see Chapters 3 and 5).

Why can't we rely on legal guardianship? Parents are often unaware that they cease to be the natural legal guardians of their sons and daughters at the age of majority. For them to continue as guardians, their son or daughter must be judged incapable by court order and a guardian appointed to make financial, medical and legal decisions for that person. The drawbacks of guardianship are that all decision-making power is removed from the person, with all citizenship rights so that, in the eyes of the law, he or she is no longer a person. Obtaining a guardianship order is also costly and time-consuming.

It is possible to keep a son or daughter safe without resorting to legal guardianship. As Al Etmanski points out in ***A Good Life*** (PLAN, 2000; Chapter 5: "Ensuring Choice", p. 183), a Supported Decision-making Agreement can be recommended. Here are the advantages from the point of view of a vulnerable family member:

- *I actively participate*
- *My views are sought and taken into consideration*

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- *I am surrounded by caring, knowledgeable and trustworthy people who can assist with my decision-making, support my communication, and listen to and interpret my decisions*
- *My needs are the primary consideration, not those of the staff or service system*
- *The focus is on my abilities and wishes*
- *All my choices and options are considered*
- *My tastes, preferences, motives and ability to discriminate are taken seriously*
- *My risks, failures and mistakes are recognized as learning opportunities*
- *My intuition and feelings have as much weight as my intellectual ability*
- *All my methods of communication, both verbal and non-verbal, are recognized as valid."*

There are three broad areas of decision-making for a person with a disability:

- Health/medical (emergency and routine) decision-making
- Financial decision-making
- Personal care decision-making

A durable/enduring power of attorney is a good idea for the first two areas, but a more comprehensive Supported Decision-making Agreement (SDMA) is compatible with this too.

An incorporated entity of personal support or Aroha (see Chapter 3) fits perfectly with an SDMA, with three or more directors sharing knowledge and responsibilities for health/medical, financial and personal care matters.

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Organizations that support family groups to form personal networks, such as PLAN, also recommend an SDMA. Some local PLAN networks may offer the services of their community connectors or facilitators as monitors.

Reasons for discussing and making an SDMA:

- The process is powerful and useful in helping the person with a disability to become accustomed to making decisions.

- The SDMA is a tool to strengthen existing relationships, involve others, and thus help a personal support network to grow and increase its commitment to the person. An SDMA provides status to family and friends and involves a broad group of people who reflect the person's multi-faceted nature.

- The existence of a SDMA creates at least moral authority for assisted or supported decision-making. So far only some jurisdictions clearly recognize SDMAs. Yukon was the first Canadian province to do so, and British Columbia now recognizes the equivalent Representation Agreement. The pace of recognizing the case for a SDMA has quickened in the past 2-3 years. If enough people make SDMAs, the moral authority will influence legal authority, as has happened with "living wills" and "health care consent forms".

- SDMAs can enhance existing enduring powers of attorney.

Key components of an SDMA:

- Person with a disability must initiate it.

- Should address three areas: financial/business, health, daily living/personal care.

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- Should convey an understanding that decision-making assistance will be based on person's values, beliefs, experiences, preferences—and not on what is perceived by others to be the person's best interest.

- Should identify the ways in which the person expresses preferences, makes choices and conveys understanding, and if necessary witnesses who are expert in that system of communication and/or know the person well.

- Should contain a clause stating that the intention is to assist and support decision-making while recognizing that an SDMA does not yet have legal power in all jurisdictions.

- Can identify one or more supporters (individuals to assist with decision-making), with each person's area of responsibility, and name which person may speak on behalf of others, a process for resolving disagreements, and any alternate or replacement.

- Could appoint a monitor who knows the person, is willing to stay in regular contact, and able to:
    - ensure the SDMA is working
    - prevent abuse and exploitation
    - give support and assurance
    - act as contact for person and supporters

People with severe autism may endure periodic health challenges that can affect their ability to communicate with Supported Typing. For this special reason, it is possible and may seem wise to include a Ulysses Clause or Ulysses Agreement in future planning for all contingencies as part of an SDMA.

A "Ulysses Agreement" lets a person plan for episodes of intermittent incapacity that may leave them temporarily unable to make decisions of their own. A person

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can, when in good health, communicate instructions for times when they would be unable to type or otherwise express their wishes. The name comes from the epic story of Ulysses who told his men in advance to keep him from temptations when he might not make wise decisions.

The Ulysses Clause or Agreement has been used by people who are intermittently unable to make responsible choices because of mental illness, such as bipolar disorder. It may also be used by people facing serious illness or dementia. It can also be helpful for people on the autism spectrum who may have hard times alternating with lucid and competent periods. Someone who cannot rely on his voice and uses Support Typing to communicate can plan for times when he may be so distressed and incapacitated that he could not concentrate on typing.

One man we know suffers tonic clonic seizures as well as prolonged periods of stress when he cannot think straight. With Supported Typing, he has told his supporters what specific forms of medical treatment he is willing to have. He hates and fears hypodermic needles. But he may agree that, if he has suffered concussion during a seizure, he needs a needle to receive local anaesthetic for stitches to his head. He would agree that, even if fear drives him to resist medical attention, he wants his supporters to reassure and help him to submit. On the other hand, he could also veto any kind of psychotropic medication to calm him, as he is allergic and has had paradoxical reactions to all drugs in the past. He has also stated that "I want to die when there is still life in me. I don't want to be kept alive if I am on a machine—not at all!"

These provisions must be formally written into a SDMA (Appendix 1) and witnessed and accepted by a person's supporters. Then supporters are empowered, at such times, to remain faithful to the original instructions and to act on the person's behalf in the way previously decided.

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3 Aroha Entities for Personal Support

The most valuable resource for a person with a disability, as for most of us, is a circle of friends or a personal support network. For someone who is vulnerable, it is wise to consider incorporating a formal, legal entity to supplement or succeed the role of parents in ensuring the person has a good whole life. The Aroha entity, developed by GSA as an integral part of its model, is the incorporated core of a person's circle of friends. GSA as a housing trust has the powers to ensure each person's longterm occupancy of their own home. But GSA is set up to support several individuals to have their own homes, and there might be times when the interests of individual members differ. GSA relies on each Aroha to have a unique focus on the individual person and to advocate with and for the person.

Our experience in developing the Aroha concept and mechanism has led others besides GSA's active members to decide to create Aroha entities.

The first Aroha in Ontario was incorporated in 2002 with and around a man in Guelph. This Aroha has shared its experience with other circles of families and friends who want to incorporate. One condition of an agreement with GSA for a home of one's own is that the person has an incorporated Aroha.

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An Aroha entity can be helpful in many circumstances, whether or not a person wants to live in a home of his own. Each vulnerable person and situation is different and unique. If you are considering incorporating an Aroha around your loved one, you should think through what you need and consult your lawyer. You might read the advice in our Questions and Answers below, and consider especially the following questions:

- We already have a circle of friends and a personal support network. Do we need a legally incorporated Aroha entity as well?
- Whom can we ask to be directors on our incorporated Aroha entity?
- How can we start an incorporated Aroha entity around our relative with a disability?
- What are the legal requirements for an Aroha entity for personal support in Ontario?
- How can such an Aroha entity maintain our son/daughter's good life when we no longer can?

What is an Aroha entity for personal support?

An Aroha is formed when a group of committed family members and friends join together with a person who is vulnerable because of disabilities to incorporate an organization according to the laws of the province, state or nation in which they live. This entity has the objects and legal powers to address the vulnerable person's planning and support needs, to create solutions, and to manage resources in ways that are responsive and accountable.

The Maori word "Aroha" (from Aotearoa/New Zealand) is used as the generic term for incorporated entities for personal support. Aroha entities are very

similar to "microboards" in British Columbia or "self-directed support corporations" in various American states.

Aroha means the various qualities and values that are needed in a caring circle of friends. Its meanings include affection, sustaining love, charity, compassion, empathy, concern, trust, pity, understanding and true friendship—all in active ways, not just ideas or feelings.

Who should be interested in Aroha entities for personal support?

Incorporated Aroha entities have great potential interest for:

- Persons who have disabilities that make them vulnerable or socially isolated and limit their abilities to carry through business decisions about their lives. An incorporated Aroha entity should be an option for anyone who has a developmental, physical, mental, cognitive or communication disability.
- Everyone who cares about a relative or friend with a disability, as an Aroha can provide a platform for inviting community support to broaden and continue the good things being done by family and friends.
- Communities who can see the benefits of families and friends having real and responsible roles in protecting vulnerable and otherwise socially isolated persons from abuse, and generally promoting safety in communities.
- Governments who are reassured that, with its legal powers and responsibilities, the incorporated Aroha entity functions enough like an agency to receive disability support dollars and provide fiscal management.
- Prospective foundation supporters who appreciate Aroha entities for their success in leveraging family and community investments.

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What can an incorporated Aroha do for personal support?

In essence, ensure that available resources and supports are used for the individual, in keeping with her/his wishes and needs—now, and into the future, after parents are no longer available to take care of the many details that add up to quality of life.

First, members and supporters of the Aroha entity ensure that the person with a disability has ways to understand options and make decisions about her/his life. GSA recommends a supported decision-making agreement.

Second, an incorporated Aroha entity can have legal powers to:

- receive and administer individualized funding directly from Government,
- administer trust funds set up by families,
- be the employer of record for support workers,
- own and maintain property such as the home of the person with a disability,
- make contracts and agreements with independent service providers and consultants,
- make contracts with facilitators and agencies that may provide "second-level" supports,
- carry liability insurance.

This seems a new idea: has its value been proven anywhere?

Aroha entities for personal support may be new for Ontario. However, entities called microboards, with similar powers and functions, have already proved themselves since the 1980s in western Canada.

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- The Microboard was invented and named by David Wetherow in Winnipeg in the mid-1980s, as a creative response to the movement of Manitobans out of long-stay institutions.

- Entities called microboards are most numerous in British Columbia where over 800 have been created since the first pilot project in 1989 by the Vela Microboard Association. There are now more than 600 active microboards in BC, each of them a vehicle for the practical involvement of many more over 700 friends and family members. Vela provides exchange of information and support at its website.

- Microboards are also being created in various US jurisdictions, Tennessee for example, but these entities also have the generic name "self-directed support corporation".

Ontario has a different corporate legal structure from western Canada, so the process of incorporation and the legal powers of Aroha entities are different from microboards, though the intent and effect are similar.

We already have a circle of friends and a personal support network. Do we need an incorporated Aroha as well?

Circles and networks can all help persons with disabilities to have better lives. All stress the critical importance of relationships with friends. All are ways that a family can invite friends and community allies to understand the needs and values of its relative with a disability and to help plan for a more secure future.

Friends in circles, networks and incorporated entities (such as Aroha, microboards, self-directed support corporations) would agree that the elements of a good life and a secure future are, as presented in *A Good Life* by Al Etmanski of PLAN™:

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- Sharing your vision
- Building relationships in a strong circle or network of friends
- Creating a home that offers sanctuary
- Making a contribution
- Ensuring choices
- Developing your will and estate plan
- Securing the plan

PLAN™ creates personal support networks that are more formal and more enduring than circles of friends. PLAN and its affiliate organizations are committed to maintain lifelong networks around the relatives of lifetime members and to monitor their quality of life and services.

A legally incorporated entity, such as Aroha or microboard, is definitely more formal than a circle of friends or a personal support network on the PLAN model. It may be chosen by families with one or more of these characteristics:

- Few or no near relatives to take trustee roles when the parents are no longer able to support their daughter/son
- A wish to help kind friends who may assume roles as directors by more exactly defining their responsibilities and giving them legal powers
- A focus person with complex needs including difficulties of communication
- Disabilities and circumstances that call for individualized supports and funding.

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Whom could we ask to be directors of our incorporated Aroha?

We may think that those who become directors of boards are typically lawyers, accountants, businessmen or ex-politicians. These people can bring useful skills and connections to any incorporated entity on which they serve.

But far more important as directors of an Aroha entity for personal support are those who really know and respect the focus person through spending good time together and "deep listening" to what the person says is most important in his life. Directors who share the values of the focus person and his family can use their legal powers to ensure that all available resources are responsibly used to support a good life.

The focus person and some family members may certainly be directors of an incorporated Aroha entity. It is good to plan for 4-5 other directors who are of different ages, abilities and interests and can bring various skills and connections to their roles. No individual who is currently paid to support the focus person can be a director.

Parents and siblings of persons with disabilities may feel short of friends. They have usually been too preoccupied with the special needs of their child to develop a wide range of good social relationships. They have had to be disciplined and self-reliant to survive. They may not feel they have been sympathetically supported by extended family members. They may hesitate to ask their few friends to take on what they imagine will be considered an unwelcome task. Families with autistic sons or daughters may feel particularly isolated and short of friends.

We should know that there are people who care about our family. These friends may not have known how to help and may welcome an opportunity to be of

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service, especially when the roles are well defined. They may respect us for planning for the future. They may see their experience on such an entity as valuable for future responsibilities in their own families, with elderly parents for example. They may even find joy and fulfillment in getting to know other friends in the circle /network and entity.

Families who may not feel brave enough directly to ask friends and relatives to be part of the circle of friends or Aroha entity, may hire a facilitator to help them.

How can we start a legal Aroha entity around our son/daughter?

First, think through all the following questions. Don't rush this phase, as it is essential to the longterm success of the Aroha entity and a good life for the person with a disability.

- Do we really need an incorporated Aroha entity, or would our family, circle of friends, or personal support network be enough for our relative's needs, now and in the future?
- What do we want the Aroha entity to do, now and in the longer-term future?
- Who of our relatives and friends would be willing and able to be directors? How well they know our relative with a disability? What gifts and abilities will they bring? Do they represent various ages, abilities and interests?
- Can we handle the work of incorporation or do we need to engage a lawyer?

What are the legal requirements for incorporating an Aroha entity in Ontario?

It is quite possible to set up a not-for-profit corporation without share capital in

Ontario with the objects of obtaining and managing supports for a named individual. The founding directors may feel able to handle most of tasks of incorporation, or you may consult a lawyer. See the *Not-for-Profit Incorporator's Handbook,* by the Ontario Attorney-General (available online for download).

This is the sequence of tasks in incorporating an Aroha entity:

a) Choose a corporate name. An appropriate name might be: "Friends of [person's name]", for example, "Friends of Adam Smith." You will have to pay an approved searcher of records to ensure that the name you choose is not already in use and to produce what is called a NUANS Report. For a corporate name that includes the name of a living person, you will also have to get the approval of that person.

b) Download (or otherwise obtain) the form for the Application for Incorporation of a Corporation without Share Capital (Ontario).

c) Complete the form with the following information:

i. corporate name

ii. address (which may not be a post office box)

iii. full names and addresses of all persons who are to be directors (For the Ontario Companies Branch, there must be at least three directors aged at least 18; it is advisable to have between 5 and 7 directors of an Aroha entity for personal support)

iv. objects of incorporation, with the principal object stated first, then secondary objects if any. It is advisable to keep the objects short but broad in nature. The objects of a corporation without share capital cannot contain a clause contrary to Section 126 of the Corporations Act which states that a corporation shall be carried on without the purpose of gain for its members.

v. Under special provisions, a non-profit non-charitable corporation must include the "No Gain for Members" clause which is pre-printed on the form. You may also state the provision that, on dissolution of the corporation and after payment so all debts and liabilities, any remaining property shall be distributed or disposed of to charities.

vi. Names, addresses and signatures of the applicants for incorporation; these must include all the persons identified as directors in iii. above.

d) Submit the completed forms in duplicate with the NUANS report and the incorporation fee to the Companies Branch in Toronto. On top of the basic fee, one can request expedited processing within 10 business days for an added fee.

e) When starting up an entity for personal support, you should also draft relevant bylaws to guide the directors on membership, election and qualifications of directors, and requirements and procedures for meetings and records.

f) Directors should also be aware of the ongoing responsibilities of an Ontario non-profit corporation--as to filing, changing any legal information, record-keeping, auditor, and meetings. For information about these ongoing responsibilities, see "Corporate Maintenance" online from the Ontario Attorney-General.

How can an incorporated Aroha entity maintain our son/daughter's good life when we no longer can?

- An Aroha entity that has practised administering the necessary supports and services during the parents' lifetime is able to keep these going smoothly through the time of emotional loss.

- An Aroha entity that is committed to "listening" to the person with a disability through, for example, a supported decision-making agreement, will continue to respond to the person's changing needs and evolving abilities.

- An Aroha entity that continues to recruit new friends and community allies and to renew itself will keep expanding the person's network of relationships

- An Aroha entity may be named as a trustee for special funds that may be set up under the parents' wills.

How the Aroha entity works—in implementing the person's choices and in sustaining a person's good whole life into the future—is discussed further in Chapter 5, Aroha in Practice. Appendix 2 offers model objects and bylaws for an Aroha. The relationship between the Housing Trust and Aroha is spelled out in Appendix 4. The Aroha of anyone supported by GSA is also a party to all the other agreements in Appendices 5, 6, 7 and 8.

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4 GSA as Housing Trust

Trust is the vital quality in GSA's role for our active members and their families and friends. The primary role of directors of the GSA Board is to be good trustees for the well-being of our vulnerable citizens and of the funds that support their good lives. In its primary function as a housing trust, GSA's roles and responsibilities are carefully defined in legal agreements.

What is a Housing Trust? Guelph Services for the Autistic uses the term with two levels of meaning. One is the sum of the formal and informal relationships of trust around each person, when an agreement is made to support the lifelong occupancy by a vulnerable person in his or her own home. Such an agreement is legally defined and subject to several conditions.

The term is also used for the mission and focus of the charitable not-for-profit corporation that has embraced the vision, mission and function of making these agreements with individual persons and may support several vulnerable persons in homes of their own. It is helpful that GSA's charitable status can entitle its properties to exemptions from local property taxation, when they are used for GSA's charitable purposes. Tax-creditable receipts may also be issued to donors who give to GSA for its charitable work.

The term Housing Trust has been used to mean a fund or mechanism for creating affordable housing in municipalities and regions all over the world, with several

safeguards—usually involving public funding. We share that general function, but with a special emphasis on supporting a person with a disability (autism in our case) to have his or her own home. Our use of the term also involves more shades of meaning of "trust"—so that persons and their families can trust that good arrangements, made in advance, will be carried out. Trust is involved among more partners with more safeguards for the person's well-being.

Guelph Services for the Autistic (GSA) is a charitable, not-for-profit organization, incorporated in Ontario since 1980, that reorganized itself in 1997 as a housing trust. GSA's mission is to help adults with autism to live good whole self-directed lives in their own homes, supported by people they choose, and included in their communities. GSA does this by holding and administering property in trust for each person's lifetime, subject to necessary personal and financial safeguards.

GSA is concerned that all supports in a person's life are well planned and co-ordinated to form the basis for a good whole life. For each person with whom GSA makes a commitment to support in a home of their own, there must be assurances that all the costs of occupancy will be covered. So far, this has meant a commitment by the person and his or her family to contribute private funds for the capital costs of the home and to negotiate any support dollars for which the person may be eligible. The finances of each person's plan are kept in separate bank accounts. GSA's relationship with each person is defined in distinct agreements. GSA must do everything possible to protect the person's home for their lifelong occupancy. This is such a serious process that GSA discourages family groups from acting hastily to purchase a property to be the home of a vulnerable person until decision-making and an Aroha are in place.

Each person supported by GSA must have an Aroha, an incorporated entity with directors representing the circle of friends, to be responsible for most aspects of

personal support including supported decision-making. An Aroha is valuable now and vital in the longer term to sustain the person's good whole life. GSA depends on each person's Aroha to take responsibility for support workers and caregivers and the co-ordination of everyday life to ensure successful occupancy. An Aroha should be active before a family group begins to buy a house.

GSA has not been a transfer payment agency and does not seek regular government funds. All GSA work has been done by volunteers; there are no paid staff. This might change in future with an increase in the number of people supported in their own homes by GSA.

To encourage vulnerable persons and the families and friends to plan well, GSA has also organized events or sheltered various projects and information services that support its mission. Bridges-Over-Barriers is an ongoing project, dedicated to helping adults who cannot use their voices to express themselves reliably in alternative ways. The Ontario Adult Autism Research & Support Network (OAARSN) website and Listservs offer opportunities for support, encouragement and information sharing and promotes positive and respectful approaches in supporting adults with autism.

GSA's bylaws are similar in many ways to those of any charitable not-for-profit corporation in Ontario that supports human and social services. There are two distinctive features that ensure that the interests of adults with autism are always of central importance in the board's decisions.

One is in the membership structure. "Active members" are persons with autism who are signatories to a current and binding Occupancy Agreement with GSA. "Associate members" are persons who wish to support GSA, usually because they are family members or friends of a person with autism. "Proactive

members" are persons with autism who are interested in discussing an Occupancy Agreement with GSA. Another feature of GSA's constitution is the election of up to four GSA directors directly by "active" members.

More generally, it is important that directors and prospective directors of the GSA Board are trustees for the good, whole sustainable lives of our adults with autism. Directors of a housing trust should be:

- Sensitive to the values and spirit of GSA, in relation to people who are vulnerable because of disability--including the presumption of competence, the right to communicate and to direct one's own life, and the insight that a person's good whole life must be grounded in their own priorities and choices and in support by family and friends.

- Reliable and trustworthy members of the community so they can be responsible trustees for the long-term interests of adults with high and complex support needs, and for the house properties maintained by the a housing trust.

- Well connected with the community and thus with helpful resources relevant to administering and maintaining a home, and who offer community connections to increase our effectiveness.

- Aware of the legal requirements of being a director of a not-for-profit corporation with registered charitable status.

See Appendix 3 for the constitution of GSA as a housing trust. GSA supports or is a party to all other agreements in the Appendices.

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5 Aroha in Practice

A Guelph man supported by GSA was the first person in Ontario around whom an Aroha was formed. Andrew was a pioneer in creating a home of his own as a basis for a good whole life. He was fortunate that his parents were willing to pay for his home, and also that he had some individualized funding with recognized powers to direct how the funds should be used. He also had good friends who cared about him and met with him from time to time in ones or twos or as a full support circle.

But Andrew's family consisted only of his parents who were fully committed to him but aging. In 2000, Andrew started to express his apprehensions about the future:

> *I am very anxious about how my life will be supported in future. I want to talk about fear. I am terrified when night comes and I fear that I will be left alone. The thing I am scared about is seeing the day my parents die. I believe that we must move as quickly..... to get things moving. I really want to feel secure... to know who will live here. I'm concerned about my future security. I need to know my means of support. I need to know that there is a safety system. I want to live in my house forever. I want to mind my own life as much as possible. I need to lessen dependence on my parents. I need people to count on.*

Andrew's parents and friends responded in several circle meetings that addressed ways of making new connections with and for him. They also proposed study of the entities called microboards, an idea taken up by GSA which offered Guelph Focus on Microboards to about 60 participants from across Ontario in November

2001. David and Fay Wetherow, who led the workshops, had developed the first microboard in Canada—in Manitoba in the mid-1980s--and then consulted to various groups and governments in Canada and the United States.

Andrew's parents and circle of friends were so encouraged by the Wetherows' message that they decided to apply for incorporation in Ontario of an entity of personal support. This became effective in February 2002. Since the word microboard had been reserved and patented by a British Columbia organization, Andrew's supporters looked for an alternative that could be used for an entity incorporated under Ontario laws. They wanted a distinctive word to evoke the qualities of the personal support relationships that a vulnerable person needs. The Maori word Aroha (from Aotearoa/New Zealand) means the various qualities and values in a caring circle of friends--affection, sustaining love, charity, compassion, empathy, concern, trust, pity, understanding and true friendship—all expressed in active ways, not just well-intentioned ideas or feelings. Andrew was born in New Zealand, so that was another reason for choosing Aroha as the generic term.

Andrew is a director of his Aroha, together with his parents and several friends who are of different ages, all younger than his parents. Directors of his Aroha are core members of his wider circle of friends who are also members of the Aroha. The other directors of Andrew's Aroha bring various kinds of qualifications and life experience to their roles. They all know Andrew well, show respect for him, and keep in touch by sharing parts of their lives with him. One director is a specialist in speech, language and communication; she can ensure that Andrew has real opportunities to express himself and be listened to, as he does not speak with his voice. Another director (and president of the Aroha) is a professor about Andrew's age who also shares interests in physical fitness and is an honorary director of GSA, the housing trust that owns and maintains Andrew's home for his lifetime occupancy. A third director is younger than Andrew; she was his full-time tutor for

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two years, and is now a teacher and settled with her husband and children in Andrew's neighbourhood.

As soon as his Aroha was incorporated and his friends had agreed to be directors, Andrew felt reassured. He says:

> *I feel good knowing about Aroha. I know my future is safer. Proud to feel I'm a pioneer. It means there is a plan for when G and E leave this earth. Aroha keeps my home going with my voice. My Aroha friends know how to listen to my voice. I feel safer knowing that my Aroha would be in charge. Not some strangers. I'm glad that I can express this.*

Andrew's Aroha is designed for his needs and situation. The essential qualities and powers of an Aroha can be adapted for the specific needs and situations of other people who are vulnerable because of some disability. They are compatible with the values and goals of personal support networks and circles of friends, individualized funding, supported decision-making, and community building. Andrew's parents are still active in supporting his self-directed life, but the legal mechanisms are in place for a smooth transition when they are gone.

Andrew's Aroha has a vital role in GSA's model of support for a home and good life of his own, and is party to most of the agreements set out in this book—with individuals and agencies. Appendix 4 details the ways in which the Housing Trust relies on the Aroha. Directors of the Aroha have considerable powers and responsibilities to listen to him, look out for his well-being and make connections for him, as well as to advocate for and administer supports and resources to keep his good life going. Above all, though, they are friends and the core of Andrew's larger circle of friends. "My Aroha friends are important for who they are, what they can do now and what they will do to support my good life into the future." Personal relationships and trust are central, as Andrew says in this poem:

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Different people in my life
19 Nov 2011
It takes different things
to make the world work.
I need different people in my life
to make me work like I need to.
That doesn't mean
that they make me work
or they work for me.
It means I need
different people in my life.

I have people who are strong and bold:
they are like pillars
in the bridge of my life.

I have people who are gentle
and kind with a soft heart to
give me encouragement to try:
they are the bricks
in the bridge of my life.

I have people in my life
who are there when I need them—
dependable, respectable, kind people
who respond when I need their help.

People have opinions of
who I am and who I should be.
But the people in my life who matter
are people who give me
the chance to be me.

I need to be encouraged
and given the motivation
to use my determination
but I also need to be given
time and patience to make
a change or mistake.

The people in my life help me
overcome the things in life
that could leave me in the water.
I don't like to just swim.
I like to walk over the bridge.
I need each of these
unique and wonderful people.
The bricks and the pillars
build the strength of my bridge
to pass over when I need it.

I need different people in my life.
I am me because each person
allows me to be me.
The different people in my life
make me wholly me.

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6 Affording a Home of My Own

GSA's model allows parents to provide all or part of the capital to buy a home, in several options, and to have the peace of mind with safeguards for a good sustainable life in a home that revolves around their family member with a disability.

How do we translate dreams and hopes into realities? It's hard enough for able-bodied people to become homeowners. A home of one's own seems unattainable by a person whose only income is a disability allowance way below the poverty line. Anyone dependent on such an allowance is forbidden to accumulate savings and, even when given or bequeathed a home, may find it impossible to pay for all the costs of maintenance. In times when social housing funds are very scarce, it's vital to think creatively of private-public partnerships.

In one such option, parents with the means might provide funds for a separate property to be the individual home of a son or daughter from early adulthood. This contribution is recognized by GSA in a formal agreement that safeguards the family investment and also gives a family the assurance that a corporate entity has pledged responsibility to sustain the occupancy of their son or daughter.

Parents might already own a property which they then transfer to GSA, or they might provide the cash or securities with which GSA buys the property. A family may begin the purchase "in trust" if the intent is to transfer the home to GSA quite soon. It is advisable to have thought through all the implications and to have the

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Aroha already in place before completing any formal agreement to lend money for the property.

GSA makes a legal agreement with the family funders to recognize the value of such capital as a non-interest-bearing Collateral Mortgage that is formally registered on the property. GSA undertakes to support the successful occupancy of the property by their son or daughter, providing the person has an Aroha entity to take responsibility for quality of life.

In certain circumstances, the family lenders may be entitled to require GSA to repay the amount of the mortgage (adjusted to take account of changes in market value).
1. One would be if GSA fails to support the occupancy of the family member in the home.
2. A second would be if the family member dies.
3. A third circumstance would be if the person chooses to move and GSA is not able to support him or her in a different property.

Assuming the autistic person outlives the parents (or other family lenders), the agreement provides for the value of the property eventually to revert to the estate, to be disposed of under the parents' will. This is the kind of agreement illustrated in Appendix 5.

Variants of this agreement are possible in other situations. Parents may continue to support their autistic son or daughter in the family home until they are no longer capable. They may have made a conditional agreement to deed the family home to GSA at that future date, when the various agreements in this book should become effective. GSA might also take the lead in a cohousing or co-op project involving several families with their sons and daughters, some of whom might lend

capital. A modified version of this agreement might be made between GSA and a foundation or other corporate benefactor that might sponsor a home for a person who is without family resources.

"I have my own home and it revolves around me"

Endorsement by GSA's first active member, June 2003

People should know what a wonderful home I have and the things I do every day. I have my own home and it revolves around me. I know everyone who comes here is friendly to me. I'm sorry more people can't have this. I have this because my parents are good advocates and they also paid for my home. My parents, my Aroha and GSA listen to me and respect my decisions.

I think I am comfortable and safe here. My garden is heaven on earth. It is a friendly neighbourhood. I get out a lot and they see me. I like to greet people when they greet me. I try to smile. My dog is my friendmaker. I love to walk with her.

In my home, I have space to do things like music, art and the computer, and my bedroom and bathroom are private. There are sensors on the bedroom and bathroom doors if I need to get help. There is an apartment in the basement and more bedrooms upstairs and many bathrooms. It was a real adult accomplishment when I first used my electronic key to open the front door.

I'm happy with our progress. Well planned and not stressful. I grow into each step. I like to be a pioneer but it is too slow and scary sometimes. I might get the wrong people. I am interested in interviewing people to support me. It is most important that I get a say. I have lots of good people in my life.

My Aroha and GSA have promised to go on supporting me after my parents die.

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7 Rights Recognized in Occupancy Agreement

When first drafted in 1997, this agreement was innovative in several ways, and still is. It encapsulates the essence of GSA's function as a housing trust, in enabling a vulnerable person to live in his own home with dignity, respect and safety.

It is the basic and central legal agreement between the housing trust and the person. Its various clauses enable the person named in the agreement to enjoy all the benefits of lifetime homeownership and to develop his home as the basis of a whole good life, while protected against the risks of exploitation or inadvertent failure to maintain occupancy.

As well as the more conventional agreement in legal language (Appendix 6) there is a plain-language version expressed in the first person and printed out below. While the home is legally the property of GSA, which takes responsibility for its safety, maintenance and financial viability, everyone concerned regards it as the home of the person named in the agreement. Utility accounts are in the person's name, for example, and mail relating to the running of the household is addressed to him. Respect for each person who makes an occupancy agreement with GSA is also expressed in the status as an "active member" and by the power to elect directors of the GSA board.

For the relationship defined in this agreement to succeed, several other agreements are needed. GSA is a party to all except the supported decision-making agreement (Appendix 1) which it requires as a condition of supporting an "active member" who seeks its help to live in a "home of my own". The person himself and the Aroha are parties to all the other agreements except the family

funding agreement (Appendix 5) which may be needed for financial viability. Lifesharing companions, if needed to help the named person to live in his own home, are chosen by the person and make separate agreements with GSA and the other parties involved (Appendix 7).

The occupancy agreement also provides for changed circumstances of various kinds. If the named person fulfils all the stated conditions, he can remain in his home for his whole life. If the home is no longer suitable, GSA pledges to help to provide or find an alternative home under the same conditions of respect and safety.

This agreement is relevant for a single individual supported in his own home. A modified version would be needed when two or more people may share a dwelling or a building.

Model Occupancy/Housing Agreement (Sole Occupant)

AGREEMENT IN PLAIN LANGUAGE

THIS AGREEMENT made this ____ day of _____, 2_____

BETWEEN: _____GUELPH SERVICES FOR THE AUTISTIC_____
a non profit charitable Ontario corporation (the "Housing Trust" or "GSA")
AND: _____
(name of focus person, supported by family members and Aroha)

This paper gives me the right to live at _____ (address of my home).

I have the right to live in the home.

I cannot give other people the right to live in the home.

Only this paper gives me rights in the home.

I will always have my own bedroom/bathroom and can use all parts of the home except for private rooms of lifesharers.

I can start living in the home now. My right to live there will end when something in section 11 happens.

I will pay _____ rent each month to live in the home, to start with. Heat and utilities may be extra. The amounts will be reviewed each year.

If the rent changes, I will be told 60 days before the change

If I get ODSP (or other benefits) the rent will be no higher than the amount I get for rent.

If I do not get ODSP or if there is no rent part, I will not pay more than 40% of the money I get each month for rent.

Subject to other things written in this paper, I have the right to live in my home for the rest of my life.

I will pay my rent on time

I will pay for my own phone and cable TV, if I use them.

I will not change my home unless the GSA says I may. But I can paint or decorate the inside without asking.

I will not damage my home. If I do, I will pay for it.

I will help with cleaning, clearing snow and caring for the garden.

I have to insure my things. If I cannot pay for insurance, GSA will do it for me.

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GSA will keep my home safe and will fix things. GSA may also make changes to my home if I need them, but will talk to me before making any changes.

GSA will make sure that the heat and air conditioning are working. If they do not work, GSA will fix them.

If I or other people in my home cannot clean, clear snow or garden, GSA will do these tasks.

GSA will put smoke and carbon monoxide detectors on each floor and a fire extinguisher/detector in my home.

GSA will insure my home.

GSA can come into the house to check, fix and clean it, or check on me if there is an emergency.

Friends in my Aroha and support circle are most welcome to visit me any time, but should check with my lifesharers that I will be at home.

I can leave the home for a while and still have the right to live there.

If I leave for a while, I still have to pay my rent each month.

If I leave the home without telling GSA, I may lose my right to live there.

If I take most of my things and do not pay the rent, GSA can say I left for good.

GSA must try to find out if I am coming back within 60 days after I leave the home.

While I am living in the home, no other person shall have the right to live there.

Other people may live in the home to help me. If they do, they will not have all the same rights as me.

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We may agree that I can move and have the right to live in another home owned by GSA.

If I need to live elsewhere, GSA must try to give me a right to live in another home.

If I have the right to live in another home owned by GSA, the things in this paper will still apply.

If it is necessary to transfer legal ownership of my home to another housing trust, GSA and my parents, friends and Aroha must be satisfied that all my rights to live in my home continue for my lifetime.

If it costs money to transfer the home, the other housing trust will pay.

My right to live in my home will end when I say I want to leave; or if I do not pay my rent on time; or if I leave the property and take my things with me; or when I die.

I will not lose my right to live in my home if I do not pay my rent, unless GSA does the things it has to under the law.

I can say I want to leave by writing a letter to GSA or by any other way I choose.

If I tell GSA I want to leave, it will check to make sure I really want to leave. GSA will write down how they checked to make sure

After I sign this paper, I have five days to talk with someone and get out of it. The things written in this paper can be changed if I and GSA agree. Any changes will have to be written down and signed by me and GSA. I can sign this paper in any way I want to.

My parents and directors of my Aroha entity are signing this paper to protect my rights to live in my home. My parents do not have to pay rent or do the things I have agreed to do.~~~

8 *Lifesharing in My Home*

Living in one's own home, enlightened as that may be, does not by itself provide enough support for a person who is severely or moderately affected by a disability. It is vital to find, inspire and appreciate the very best supporters who can help to grow a good life and keep it flourishing. Support people may include those who are paid because this is their livelihood—as caregivers, mentors, coaches or tutors or specialists in communication, sensory integration, personal fitness, nutrition, and various kinds of therapies. Friends who are not paid, but choose to share their interests and parts of their lives, also bring valuable gifts to a vulnerable person.

Having one's own home can give an adult with a disability opportunities for another form of personal support. Lifesharers can provide companionship and help with the tasks of daily living in return for sharing the home of a person with special needs--free or at a reduced cost. Lifesharing of this kind is a fairly new concept in Ontario. At first GSA used the term "homesharing" on the model of agencies that help to match seniors or other people who have health or developmental challenges (but wish to continue living with dignity in their own homes) with caring companions who are available to live in for reduced or no rent in return for their support.

True lifesharing in which the vulnerable or disabled person owns the home (or has lifelong occupancy) must be distinguished from the "FamilyHome" in which a caring person or family owns the home and is paid a per diem rate by the Government to accommodate and care for one or more persons with a disability. (The word "homesharing" has recently come into use for this relationship.) True lifesharing also involves more than the relationship between housemates who

each have a bedroom but typically share bathroom and kitchen facilities in a house or apartment.

Lifesharers are people who derive personal satisfaction from helping to meet the special needs of the people they are living with, and from the relationships that evolve between the various members of the household. They are inspired by the ideals of inclusion and intentional community.

In the GSA model, a lifesharer is neither an employee nor a tenant. A person with a disability who lives in his or her own home makes the choices about what happens in the home and does not have to move when a support relationship might have to end.

All support people in the life of a person with a disability must be carefully chosen—most particularly those in an unsupervised position of trust, such as a lifesharer. GSA upholds the right and ability of adults with autism to be centrally involved in the process of recruiting, interviewing, choosing and monitoring lifesharers. GSA is involved because the right lifesharers make it possible for persons with a disability to make a success of living in homes of their own. GSA also depends on the directors of a person's Aroha who support the person through facilitated planning meetings, interviews and decision-making. Similar agreements are made between an Aroha and other support workers and practitioners who do not live in.

Alex, who has a full occupancy agreement with GSA, has expressed wise thoughts about the qualities he needs in lifesharers, making a distinction between two kinds. Students or recent graduates may stay for shorter times and have smaller responsibilities in his household: they are lifesharing companions who make a financial contribution below market rates in return for sharing their interests and

lives for a while with Alex. An anchor lifesharer, on the other hand, has much larger roles in helping Alex to run his household, and in ensuring that everything works well to support his good whole life. An anchor lifesharer should be able to make a longer-term commitment. Alex, whose large home could accommodate up to three lifesharers, has expressed very clear ideas about what he needs:

I want to feel that the people in my house are here for me, not because the rent is cheap. I think it will be clear by the way they react to me and by the greetings and interactions. I think I will know after two real meetings and maybe a trial overnight or weekend. Lifesharers should be interested in the environment, so the house will be run by people who care like me. I want loving people. In my mind loving people is loving God. I want to be able to teach but not be a guinea pig. I like to think I can inspire others.

Lifesharers should be different from each other, but have some beliefs and interests in common. I think it is important that they devote time to getting to know me and my needs. Some understanding and willingness to learn. Their life philosophies, caring about the environment and about others. Spirituality is essential. Balance--knowing when to encourage and when to support. I think lifestyle is the key.

The anchor lifesharer idea is perfect--like a mother, helping to keep things running, but not being my only friend. I think it is important for the anchor to be older than me but not too old. Build relationship first. The anchor person (or even couple, but no babies!) must know who I am. Yes it's like dating before marriage. Need to be organized but flexible. Not like wardens. I need to be central to the house. I know I won't be the only one but the central one. Taking responsibility for my special diet is essential. It

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is like my hostess. It will be hard to replace my mother in that way but we must be ready to accept new ways. I like this conversation. It is fun to imagine my perfect anchor woman!

I need good lifesharers and friends who listen to and understand me; I need more people to talk with me using Supported Typing. I want them to ask me questions and I can answer them. I need some framework. I want everyone to know it is important that more people try to support me with ST.

Having a part-time lifesharing companion this past summer, I felt like I had a companion and a friend. I liked having her live here because it felt like family. I liked knowing that my mother wasn't the only person I could depend on. I became more able to see another person as a companion. I put myself in a position of control. I led the way more. I really liked being out in the community more. I did more and I felt good about it. She was a good fit. I need quiet calm people and lively ones too--lively but not loud!

The GSA lifesharing agreement reproduced here in Appendix 7--with Alex, his parents, Aroha and GSA as parties with the lifesharer—is the basic one for all kinds of lifesharers. Particular roles (in this case for a companion lifesharer) are spelled out in the sample Schedule that follows the agreement.

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9 Holding Everything Together in a Whole Self-Directed Life

GSA's mission is to support adults with moderately severe and complex autism who are very different from one another. Most feel uncomfortable and even extremely upset when grouped (without consulting them and perhaps against their will) with others who are considered to have similar problems. When we shift our focus to listen deeply and to see their lives from their point of view, it makes sense to think of support that is person-centred and self-directed. We know that the more complex the needs, the more individualized the supports must be.

For the past ten years, GSA members have shared in the efforts of progressive groups to advocate for direct individualized funding support for persons with disabilities. In the past eight years the Ontario Government has seemed to be moving in this direction, but it is important to keep speaking up for the principles of self-determination, citizenship, flexibility and ease of access to direct individualized funding, and ensuring safeguards through listening to the person and independent facilitation.

When GSA developed its role as housing trust 15 years ago, we knew that our adults needed disability support funds to complement the basic income support for living expenses and any capital contributions by families to the cost of the home. GSA's first active member, Anthony, was eligible for some funds, but without a clear way of using them for his needs. With the co-operation of an enlightened administrator in another region, it was possible for these funds to be flowed through his Transfer Payment Agency (TPA) to Anthony (and later to his

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Aroha when this was formed). As this was an innovative form of (indirect) individualized funding, the people around Anthony and his Aroha and housing trust were required to agree to all sorts of safeguards absolving everyone else of any responsibility.

The Personal Support Agreement in Appendix 8 was the result. As with other GSA documents, it is expressed in the first person. It is reviewed regularly and has been revised as needed, for example when a TPA in our region was found to flow the funds. The statement of Continuous Quality Improvement in Appendix 8 has two main functions. One is to assure the TPA and Government that the funds are being used responsibly. More important from our point of view, this document is a systematic summary to guide all who support Anthony in his good whole life. Below we present a plain-language version from Anthony's point of view.

We hope that the eligibility and procedures for direct individualized funding will become more straightforward and understandable when "transformation" of developmental services in Ontario is accomplished. There will probably be changes in detail and format of agreements, but GSA will continue to advocate for the qualities and values that help adults with high support needs.

How My Good Life Is Supported With Funding
Anthony Butler's Summary in Plain Language

I want to encourage people to not give up trying for individual funding and services I think Individualized Funding has made all the difference for me. I might tell people that it is essential to get IF, because it is the only way to give people choices and options. We must have the freedom to have our own life, choose our own path,

choose our own supports. I think we need to know we can provide for our own supporters, so we can choose good ones.

I am a man with complex disabilities and high support needs, I have developed the foundations of a very good life in my community during the past 15 years. My family and friends are committed to me and believe in me. I am determined to understand my options and challenges and do my best. It is important that everyone in my life knows that I understand language and what people say, but I need Supported Typing to express myself. People need to listen and pay attention to what I say with my way of communicating.

Two organizations are very important in my good life. My housing trust (HT) owns and maintains my home and recognizes me as sole tenant for my lifetime or as long as I wish to live here. My Aroha is a not-for-profit corporation of family members and friends that, with me, has powers to receive and manage the supports I need to live a good life. Both the HT and my Aroha support my rights to express myself and to make informed choices.

I receive special funds to pay for the time and training of my tutors, coaches and caregivers, for consultations with people who are expert in my special needs, and for equipment and supplies to support my learning, communication, health and training. Special funds have been approved by the Ontario MCSS.

An agency located in our region is my transfer payment agency (TPA) as a simple banker, recognized by the MCSS. The TPA flows funds to my Aroha each month, and we report on how the funds are spent. The TPA does not charge fees for simple administration. If we ask this agency to do certain extra tasks, we might have to pay for their services.

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This is how the funding relationship among all of us will work:

1. Each month, in advance, the TPA sends a cheque for one-twelfth of the approved funds to my Aroha. We deposit this into the Aroha bank account.

2. My Aroha keeps records of all expenses and reports monthly to TPA, both about how the money has been spent and how my life is going.

3. My Aroha is responsible for the quality of support I receive from tutors, coaches, caregivers etc.

4. My Aroha is responsible for advocating for my needs, including any negotiation with the Ministry.

5. My Aroha pays HT some funds each month to maintain my home and pay for the costs of utilities and insurance. HT takes responsibility for the health and safety of my home.

My Aroha, HT and the TPA understand and share the following values and agree to the following arrangements:

1. All the service providers, agencies and people in my life support me in self-determination, my rights to make decisions that affect how life unfolds daily. My decision-making rights include employment, education, personal goals, friends, the use of community amenities, leisure pursuits, types of services and supports. I have choice in the people (paid and unpaid, formal and informal) who provide personal support and a role in describing job expectations, scheduling, supervising and evaluating them. I will make my own choices and everyone else will respect them. I will tell honestly how I feel about the support I am given.

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2. Anything written down about me is mine and I can read it when I want. All documents will be respectful of me and focus on my abilities. Personal records will be kept at my home unless I ask otherwise.

3. My special funding is to be used to support me to fulfill the objectives of my individualized plan. The funds are portable: if the agreement with a TPA ends because of dissatisfaction, the allocated funds can be used in a new agreement with a TPA that I choose. The funding is also flexible and may be adjusted to meet my changing needs.

4. XX is my Key Contact in my supportive decision-making process and my daily quality of life: she is the person to call to talk about me. XXX, president of my Aroha, is my advocate/broker to act on my behalf and with other directors of my Aroha in planning, negotiating necessary funding, reviewing and monitoring my plan, and making adjustments.

5. We will review this agreement every twelve months. Changes to this agreement must be in writing and signed by all parties. If we disagree about something, we will talk to each other about it in a timely and effective manner. We will make every effort to resolve issues and disagreements informally. If an issue cannot be resolved in this manner, we will seek mediating support in a form on which we agree. If the TPA or I (with my Aroha) want to end this agreement, we can give two months' notice, or some other term of notice if we agree in writing.

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Supported Decision-Making Model Agreement

GSA upholds the communication rights and abilities of its members, both as a matter of social justice and as a vital way of ensuring that their good whole lives are self-directed.
Supported Decision-making Agreements are recommended to ensure that adults with complex challenges and high support needs such as autism become "the authors of their own lives". These agreements should be set up while parents are still alive to support the process. The rationale and purposes of SDMAs are discussed in Chapter 2.

Date _____

Name of Grantor _____

Address _____

Phone _____

Date of Birth _____

Health Card Number _____

I am making the agreement because I need and want support and guidance from my friends in making some decisions in my life. The reasons I want supporters to help me in making decisions:

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I have discussed all this with my supporters and friends and understand the meaning and purposes of this agreement.

Supporters

1 _____

2 _____

3 _____

4 _____

Responsibilities of Supporters

A. Financial Affairs and Legal Matters:

I would like _____and _____ to support, guide and/or represent me in legal and financial matters.

If either is unavailable, I would like _____to act as the second representative.

B. Personal Care and Health Care:

I would like two of the following three supporters _____,

_____, _____, to support, guide and/or represent me in health and personal care issues.

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If only one of these three is available, I would like _____to act as the second representative.

In a medical emergency, if two supporters cannot be reached, then any one of the three supporters may act alone.

I would like my supporters to inform my parents (names and contact details) regarding significant health-related issues.

I want the supporters to agree on their decisions. If there is a disagreement between the two supporters, there will be a consultation among at least three supporters to make a decision that is acceptable to everyone present.

Responsibilities of Health Care Professionals

Any time there is a question regarding my health or well being, my supporters must be consulted.

Effective Date of This Agreement and Reviews of This Agreement

This agreement will be effective immediately upon being signed and witnessed or This agreement will be reviewed two years after coming into effect and every two years thereafter, or upon the request of myself and/or my monitor and/or my supporters.

APPENDIX A DESCRIPTION OF SUPPORTERS' RELATIONSHIPS WITH ME

APPEND1X B OTHER SUPPORTERS AND THEIR ROLES

APPENDIX C EXPRESSION OF PREFERENCES

I am normally able to express myself using Supported Typing and want my supporters to pay attention to what I say in that mode of AAC. If I am unable to

use S-T, I will try to give my supporters a clear indication of my preferences, either through eye contact or through body language, so my supporters will act based on my indicated preferences. If I have added Ulysses clauses to my SDMA, I want my supporters to act accordingly. If I have not planned for a specific situation with a Ulysses clause and if I am unable to give my supporters a clear indication of my preferences by any other mode, then the supporters will act based on their relationship with me, their knowledge, and their shared past experiences with me.

I express my preferences in the following ways:
My likes:

My dislikes:

Note: This should not be seen as the final word regarding my preferences and communication as my life can change and my abilities can evolve.

ULYSSES AGREEMENT
I hereby authorize my supporters to act in accordance with my previously expressed wishes, if for any reason I am unable to communicate at a critical time.

APPENDIX D: INFORMING RELEVANT PARTIES.
Copies of this agreement given to named persons

Signatures with Dates of Person, Witnesses, Supporters

Certificate of Witnesses

Full names and addresses of witnesses:

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We certify that:

We witnessed the signing of the SDMA made by.... (full name of grantor)

We have both reached the age of legal majority.

Neither of us is a supporter or an alternate supporter.

Neither of us is the spouse, child or parent of a supporter or alternate.

Neither of us is an employee or agent of a supporter or alternate.

We were present during the signing of the SDMA.

We understand that the grantor has had the SDMA read or communicated to him/her and has signed it freely.

The truth of this statement is certified at ..... on ....

Signatures of two witnesses.

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Model Aroha: Friends Of X ... X ... [FXX]
Bylaw #1

The case for an Aroha entity of personal support is presented in Chapter 3. This model bylaw has been used by various groups of family and friends in Ontario since the first Aroha entity was incorporated in early 2002. It is based on the procedures for incorporating and maintaining any not-for-profit entity without share capital. Please pay particular attention to the Purposes of Incorporation (Clause 1.03).

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FXX: FRIENDS OF X ... X ...
BYLAW #1

PART I - PURPOSE OF BYLAW, LOCATION OF HEAD OFFICE, AND PURPOSES OF CORPORATION

1.01 - Purpose of Bylaw

This bylaw relates generally to the transaction of the affairs of **FXX**, a non-profit Corporation without share capital incorporated under the Ontario *Corporations Act*
(Ontario Corporation) on date: 20--.

1.02 - Head Office

The Head Office of the Corporation shall be in the City of ....., County of ....., in the Province of Ontario. The directors may, from time to time, determine the specific location of the Head Office.

1.03– Purposes of Corporation

The general object is to be an Aroha for the personal support of [XX] a person with significant disabilities, who has asked trusted friends to help him to manage the supports and services he needs for a good life in his community.

The specific objects are:
1. To support XX to understand the main factors that affect his life and well-being, to respond to the initiatives he expresses, and to ensure his needs and wishes are heeded;

2. To promote the support and respect of XX by workers and friends in his community who understand how he copes with severe disorders and who respect the alternative and augmentative ways in which he communicates;

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3. Upon receiving the appropriate authority from XX and at his direction, to lawfully receive and manage funding for which he is eligible, including income support and disability support dollars from Government;

4. Upon receiving the appropriate authority from XX and at his direction, to lawfully receive and manage funds from family trusts or other special grants;

5. To monitor the quality of all supports and services provided to XX;

6. To advocate for additional supports and resources should they become necessary;

7. To monitor legislation and policies which affect him, and to assist in developing services and policies which could help him;

8. To develop sources of income as may from time to time be appropriate, including carrying on such business or other activities as are incidental to the foregoing objects;

9. To do all such other things as are incidental and ancillary to the attainment of the foregoing purposes and the exercise of the powers of the Corporation.

In furtherance of the objects, the Corporation shall have the following powers:
1. To make contracts with and pay any employees, independent service providers and consultants;
2. To enter into arrangements with tenants or lifesharers who may live in XX's residence to provide him with practical and social support.
3. To hold any and all assets in any form whatsoever to further the objects of the corporation.

Upon dissolution of the Corporation, any assets remaining after the payment and satisfaction of the debts and liabilities shall be transferred to an organization or organizations, having cognate or similar objects, which carry on their work solely in Canada.

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PART II - DEFINITIONS

In this bylaw and any other bylaws of the Corporation, the following words, unless the context requires otherwise, shall have the following meaning:

"FXX" means **FRIENDS OF X... X...**

"Corporation" means **FRIENDS OF X... X...**

"Act" means the *Corporations Act* of Ontario as amended or substituted from time to time;

"Letters Patent" means the Letters Patent incorporating FXX and any supplementary letters patent;

"Regulations" means the Regulations made under the Act as from time to time amended;

"Bylaw" means any bylaw of FXX from time to time in force and effect;

"Board" means the Board of Directors of the Corporation acting as a quorum as authorized by the constitution and these by-laws;

"Board resolution" means

i. a resolution passed at a meeting of the Board by a simple majority of the votes cast by those directors entitled to vote at such a meeting; or

ii. a resolution that has been submitted to all the directors and consented to in writing by 75 % of the directors who would have been entitled to vote on it in person at a meeting of the Board;

"Directors" means those persons who have become either appointed, elected, first or replacement directors in accordance with these bylaws and have not ceased to be directors;

"Executive" means the Executive Officers of the Corporation as defined in Part VI of this by-law;

"Member" means any person who becomes a member of the Corporation in accordance with the requirements of Part III of this by-law. Where "member" is used in this by-law, it shall be deemed to mean a member of the Corporation;

"Signing Officer" means, in relation to any instrument, any person authorized to sign on behalf of the Corporation pursuant to Part VII of this by-law;

Words importing the singular include the plural and vice versa, and words importing a male person include a female person and a corporation.

PART III - MEMBERSHIP

3.01 - Eligibility for Membership

Members of the Corporation are the applicants for incorporation of the Corporation, and those persons who support the purposes of the Corporation and are approved by the board. The board may create two classes of members: voting directors who serve on the Board of FXX and supporting members who are kept informed and may support XX's good life through their interests and connections with the community.

3.02 - Voting Rights

Only directors have voting rights.

3.03 - Membership Records

Every member shall furnish to the Corporation the address of his or her usual residence or place of business or an address to which all notices intended for the member shall be mailed or delivered.

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3.04 - Protection of Members
No member of the Corporation shall, in his or her individual capacity, be liable for any debt or liability of the Corporation beyond the amount of any subscription, dues or fees payable by him or her to the Corporation.

PART IV - MEETINGS
4.01 - Annual General Meeting
The first annual general meeting of the Corporation shall be held no later than 18 months after incorporation. Subsequent meetings must be held at least one time per calendar year, and in no event more than fifteen months since the previous annual meeting. The following business shall be conducted at the annual general meeting, which shall also be an occasion to share information with the supporting members.
(a) receiving and approving minutes of any previous annual general meeting;
(b) receiving and approving financial reports and any other reports;
(c) electing Board of Directors;
(d) appointment of auditors and authorizing the Board to fix the remuneration of the auditor;
(e) and any other business that may be properly brought before the meeting.

PART V - BOARD OF DIRECTORS
5.01 - Powers of Directors
The Board of Directors shall be responsible for:
(a) the overall direction of the Corporation;
(b) developing and approving policies of the Corporation; and
(c) managing and directing the affairs and property of the Corporation.

The directors may, on behalf of the Corporation, exercise all the powers that the Corporation may legally exercise under the Act, Letters Patent or otherwise,

unless the directors are restricted by law or by the members from exercising those powers.

5.02 - Number of Directors

The Board shall endeavour to ensure that there are at least five (5) elected directors of the Corporation, and in any event there shall be no more than eight (8) elected directors. XX shall be a director and both his mother and father may be directors.

5.03 – Qualifications

(a) Every director shall unreservedly subscribe to and support the purposes of the Corporation, and understand and respect XX's life plan and priorities.
(b) A director shall be at least eighteen (18) years of age.
(c) As far as possible, the Corporation will seek to elect directors representing people of various ages and talents.

5.04 - Term of Office

(a) The intent of an Aroha entity is to provide longterm support to the focus person, based on close knowledge of the person's priorities. Thus continuity and a trusted relationship with the focus person are more important than regular turnover of directors.
(b) If a director is unable to continue to serve, it is vital that there be a good potential successor willing to serve. So the role of the Aroha directors should be well known to the larger circle of friends, so that new directors may be recruited when needed.

5.05 - Termination of Office

(a) The office of a director shall be terminated upon the occurrence of one of the following events:

(i) if the director fails to maintain the qualifications specified in Article 5.03;
(ii) if by notice in writing to the Corporation, the director resigns his or her office and such resignation is accepted by the Board by a simple majority vote;
(b) The office of a director may be terminated by resolution of the Board if the director is absent for four (4) consecutive complete meetings of the Board of Directors.

5.06 - Vacancies
If a vacancy occurs on the Board, the remaining directors, if constituting a quorum, may appoint a qualified person to fill the vacancy. Any new director must be well known and acceptable to XX.

5.07 - Quorum
A quorum for a meeting of the Board of Directors shall be three (3) of the directors.

5.08 - Meetings of the Directors
(a) Meetings of the Board may be called by the president, vice-president, the secretary or any two (2) members of the Board.
(b) No formal notice of any meeting of the Board shall be necessary if all the elected directors are present or if those absent have indicated their consent to the meeting being held in their absence.
(c) The Board may appoint a day or days in the month or months for regular meetings at an hour to be named. If regular meetings are scheduled, no additional notice is required. A meeting of directors may also take place without notice immediately after an annual general meeting.
(d) No error or omission with respect to notice for a meeting of the Board shall invalidate the meeting or invalidate or make void any proceedings taken or had at the meeting.

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(e) The president or, in his or her absence, the vice-president shall chair any meeting of the Board. If no such officer is present, the directors shall choose one of their number to chair the meeting. The Board may appoint a recording secretary, who is not a director, and who shall have no right to vote, to take the minutes of its meetings. Otherwise, the secretary of the Corporation shall act as secretary of the Board of Directors.

5.09 - Procedure and Votes to Govern

(a) Directors of the Board shall conduct business according to the principles of consensus decision-making, trying to reach agreement on all issues. It is important that XX understand and agree to all decisions

(b) A director shall not participate in the discussion or vote on a motion or resolution with which he or she has a conflict of interest.

5.10 - Remuneration of Directors

The directors of the Corporation shall serve without remuneration and no director shall directly or indirectly receive any profits from his or her position as director. A director may be paid reasonable expenses incurred by him or her in the performance of his or her duties.

PART VI - OFFICERS

6.01 - Number of Officers

The officers of the Corporation shall be the president, vice-president, secretary, treasurer and past president. The positions of secretary and treasurer may be combined into one position where the directors consider it appropriate. Together these officers constitute the executive of the Corporation.

6.02 - Election and Term of Officers
The officers shall be elected by Board of Directors from amongst themselves each year at the first meeting of the Board of Directors following the annual general meeting. The officers shall serve until the next annual general meeting or until he or she resigns in writing or is removed from office by resolution of the Board of Directors.

6.03 - Vacancies
If a vacancy occurs in any office, the Board, at its next meeting, may appoint a qualified person to fill the vacancy for the remainder of the term.

6.04 - Duties of Officers
The officers of the Corporation shall have the following duties:
(a) President - chair all meetings of the Corporation and of the Board, when present in person and able; have general supervision of the affairs of the Corporation; sign all by-laws and execute any documents as may be required by these by-laws; perform any other duties which the Board may, from time to time, assign;
(b) Vice-President - exercise any or all the duties of the president in the absence of the president or if the president is unable for any reason to perform those duties; and perform any other duties which the Board may, from time to time, assign;
(c) Secretary - keep and maintain the records and books of the Corporation, including the registry of officers and directors, the registry of members, the minutes of the annual general meetings or special meetings and meetings of the Board, the by-laws and resolutions; have custody of the corporate seal; certify copies of any record, registry, by-law, resolution or minute; give notice as required for the annual general meeting, special meetings and meetings of the

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Board of Directors; and perform any other duties which the Board may, from time to time, assign; and
(d) Treasurer - keep and maintain the financial records and books of the Corporation; sign cheques or other documents as may be required under these by-laws; assist the auditor in the preparation of the financial statements of the Corporation; and perform any other duties which the Board may, from time to time, assign.

PART VII - BUSINESS OF THE CORPORATION

7.01 - Fiscal Year

The fiscal year of the Corporation shall end on March 31st of each year.

7.02 - Signing Officers

The Corporation shall have a minimum of three (3) signing officers who are Board members and one (1) of whom shall be the treasurer of the Corporation. In addition, the Board may appoint, as it sees fit, additional signing officers who are not directors. All contracts, obligations, transfers, cheques and other corporate documents may be signed on behalf of the Corporation by any two (2) officers, one of whom must be a director of the Corporation.

7.03 - Banking Arrangements

The banking business of the Corporation shall be transacted with such banks, trust companies, or other financial institutions as may, from time to time, be designated by or under the authority of the Board. Any banking business shall be transacted with such agreements, instructions and delegations of power as the Board may, from time to time, prescribe or authorize.

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7.04 - Auditors

This part applies only when the Corporation is required or has resolved to have an auditor.

(a) The first auditor shall be appointed by the Board which shall also fill any vacancy occurring in the office of auditor.

(b) At each annual general meeting, members of the Corporation shall appoint an auditor to hold office until he is re-elected or his successor is elected at the next following annual general meeting.

(c) An auditor may be removed and shall be promptly informed in writing of his appointment or removal. The Board shall appoint auditors for the Corporation to hold office during the next year following or until successors are appointed.

(d) No director or employee of the Corporation shall be auditor.

(e) The auditor may attend general meetings.

(f) The Board may choose to appoint an Audit Committee consisting of two or more members of the Corporation who are not either directors or employees.

7.05 - Borrowing Powers

In order to carry out its objects, the Board may, on behalf of and in the name of the Corporation, raise or secure the payment or repayment of money in any manner it decides including the granting of guarantees, in particular, but without limiting the foregoing, by the issue of debentures.

7.06 - Agents and Employees

The Board may appoint any agents and retain any employees that it considers necessary. The persons appointed or retained shall have the authority and shall perform the duties prescribed by the Board. The remuneration for any agents or employees shall be approved by the Board by resolution.

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PART VIII - INDEMNIFICATION

The Corporation shall indemnify and save harmless the directors, their heirs, executors and administrators, and estates and effects, respectively from time to time and at all times from and against:

(a) all costs, charges and expenses whatsoever that he or she sustains or incurs or about any action, suit or proceeding that is brought, commenced or prosecuted against him or her, for or in respect of any act, deed, matter or thing whatsoever made, done or permitted by him or her in the execution of the duties of his or her office; and

(b) all other costs, charges and expenses that he or she sustains or incurs in or about or arising from or in relation to the affairs except costs, charges or expenses that are occasioned by his or her wilful neglect or default.

The Corporation may purchase and maintain insurance for the benefit of any or all directors, officers, employees or agent against personal liability incurred by any such person as a director, officer, employee or agent.

PART IX - ENACTMENT AND AMENDMENT OF BYLAWS

(a) Bylaws of the Corporation may be enacted, repealed, amended, altered, added to or re-enacted in the manner contemplated in, and subject to the provisions of, the Corporations Act.

(b) Subject to the provisions of Sections 9 (c) and 9 (d) hereof, all prior bylaws, resolutions and other enactments of the Corporation heretofore enacted or made are repealed.

(c) The provisions of Section (b) shall not extend to any bylaw or resolution heretofore enacted for the purpose of providing to the Board the power or authority to borrow.

(d) Provided however that the repeal of prior bylaws, resolutions or other enactments shall not impair in any way the validity of any act or thing done pursuant to any such repealed bylaw, resolution or other enactment.

PART X - DISSOLUTION

10.01 - Requirements for Dissolution

The Corporation is expected to last for the lifetime of XX. The organization may be dissolved following four-fifths (4/5ths) vote of the votes cast by members at a meeting called specifically to consider a motion of dissolution. The membership shall receive sixty (60) days prior notice of any meeting to consider a motion of dissolution stating the purpose of the motion and the specific date, time and place of the meeting

10.02 - Winding Up and Disposition of Assets

Upon dissolution of the Corporation, any asset remaining after the payment and satisfaction of the debts and liabilities shall be transferred to an organization or organizations having cognate or similar objects which carry on their work solely in Canada.

PART XI - EFFECTIVE DATE

This bylaw shall come into force without further formality upon its enactment.

PASSED by the Board of Directors and sealed with the corporate seal this

day of , 200..

President **Secretary**

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Guelph Services for the Autistic
By-Law #1

GSA's constitution and by-laws (originally drafted in 1980) were thoroughly revised when its board decided in 1997 to become a housing trust helping adults with autism to live in their own homes. As a not-for-profit corporation without share capital in Ontario, GSA is also a registered charity that reports to the Charities Branch of the Canada Revenue Agency. GSA has the legal powers to undertake any projects that support its main purpose as housing trust. GSA's roles and status are described particularly in Chapters 1 and 4. GSA is party to or supports all the other agreements made by its active members with their Aroha entities.

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Guelph Services for The Autistic
By-Law #1

PART I -PURPOSE OF BY-LAW, LOCATION OF HEAD OFFICE AND CORPORATE SEAL

1.01 - Purpose of By-Law

This by-law relates generally to the transaction of the affairs of Guelph Services for the Autistic, a Corporation without share capital incorporated under the Ontario *Corporations Act* (Ontario Corporation #453617) in August 1980.

1.02 - Head Office

The Head Office of the Corporation shall be in the City of Guelph, or the County of Wellington, in the Province of Ontario. The directors may, from time to time, determine the specific location of the Head Office.

1.03 - Corporation Seal

There shall be a Corporation seal for the Corporation.
An imprint of the seal is impressed in the margin.

PART II - DEFINITIONS

2.01 - Definitions

In this by-law and any other by-laws of the Corporation, the following words, unless the context requires otherwise, shall have the following meaning:

"GSA" means Guelph Services for the Autistic;

"Corporation" means Guelph Services for the Autistic;

"Act" means the *Corporations Act* of Ontario as amended or substituted from time to time;

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"Regulations" means the Regulations made under the Act as from time to time amended;

"By-law" means any by-law of GSA from time to time in force and effect;

"Letters Patent" means the Letters Patent incorporating GSA and any supplementary letters patent;

"Active Member" means an individual who is admitted to the membership of the Corporation under paragraph (a) of Article 3.01 of this by-law;

"Associate Member" means an individual who is admitted to the membership of the Corporation under paragraph (b) of Article 3.01 of this by-law;

"Pro-active Member" means an individual who is admitted to the membership of the Corporation under paragraph (c) of Article 3.01 of this by-law;

"Board" means the Board of Directors of the Corporation;

"Executive" means the Executive Officers of the Corporation as defined in Part VI of this by-law;

"Lifesharer" means an individual who lives in property owned by the Corporation for the purpose of providing support or companionship to individuals who are active members;

"Meeting of Members" includes annual general meetings of members and any special meetings of members;

"Member" means any person who becomes a member of the Corporation in accordance with the requirements of Part III of this by-law. Where "member" is used in this by-law, it shall be deemed to mean a member of the Corporation;

"Occupancy Agreement" means an agreement between the Corporation and any individual with a developmental disability for the purpose of granting a right of occupancy in property owned by the Corporation;

"Signing Officer" means, in relation to any instrument, any person authorized to sign on behalf of the Corporation pursuant to Part VII of this by-law;

"Voting members" means members admitted to the membership under paragraphs (a) and (b) of Article 3.01 of this by-law.

PART III - MEMBERSHIP

3.01 - Eligibility for Membership

The following persons shall be eligible for membership in the Corporation:

(a) "Active members"-- Individuals with Autism who are signatories to a current and binding Occupancy Agreement with the Corporation
(b) "Associate members"-- Individuals who have indicated a desire to be a member of the Corporation, and have submitted an application for membership to the Board, which the board has approved.
(c) "Proactive members" – Individuals with Autism who are interested in discussing an Occupancy Agreement with the Corporation. Proactive members can be accepted by simple majority resolution of the Board. Such proactive members do not have voting rights.

3.02 - Admission to Membership

(a) Any individual who is eligible for membership under paragraph (a) of Article 3.01 shall automatically be a member of the Corporation, should such individual so choose.
(b) Any individual who is eligible for membership under paragraph (b) or paragraph (c) of Article 3.01 may be accepted as a member by a simple majority resolution of the Board, provided that the Board shall not be forced to consider any application nor vote by resolution on any application within 45 days of the annual meeting of members.

3.03 - Membership Fees
There shall be no set membership fee for any category of membership. Donations are appreciated and official tax receipts will be issued for donations of at least $25.

3.04 - Voting Rights
(a) Subject to Article 3.04 (c), each individual who is eligible for automatic membership under paragraph (a) of Article 3.01 shall be entitled to one (1) vote and shall be considered a voting member.
(b) Subject to Article 3.04(c), each individual who is eligible for and is admitted as a member under paragraph (b) of Article 3.01 shall be entitled to one (1) vote and shall be considered a voting member.
(c) Beginning in calendar year 1998, all voting members must be admitted to the membership at least 30 days prior to exercising a right to vote at any meeting of members.

3.05 - Other Rights of Members
Every individual member in good standing and, where applicable, who has paid the annual membership fee for that year is entitled:
(a) to attend any meeting of the Corporation; and
(b) where a member is a voting member, to vote at any meeting of the Corporation; and
(c) where a member is a voting member, to run for election to the Board of the Corporation.

3.06 - Termination of Membership
Membership shall cease:
(a) upon the death of a member;

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(b) if a member has not renewed his or her membership; and, where applicable, has not paid the annual membership fee within thirty (30) days from the end of the membership year;
(c) if the member resigns by written notice given to the secretary;
(d) if the member no longer qualifies for membership in accordance with these by-laws; or
(e) if the membership has been terminated by a vote of at least two-thirds (2/3rds) of the voting members at a meeting duly called for that purpose. Notice of the meeting shall be served upon the member and shall set out the grounds for the proposed termination of his or her membership.

3.07 - Year End
The year end shall be December 31st.

3.08 - Membership Records
Every member shall furnish to the Corporation the address of his or her usual residence or place of business or an address to which all notices intended for the member shall be mailed or delivered.

3.09 - Protection of Members
No member of the Corporation shall, in his or her individual capacity, be liable for any debt or liability of the Corporation beyond the amount of any subscription, dues or fees payable by him or her to the Corporation.

PART IV - MEETINGS OF MEMBERS
4.01 - Annual General Meeting
The annual general meeting of the Corporation shall be held at least one time per calendar year, and in no event more than fifteen months since the previous

annual meeting. The following business shall be conducted at the annual general meeting:
(a) receive and approve minutes of any previous annual general meeting;
(b) receive and approve financial reports and any other reports;
(c) election of Board of Directors;
(d) appointment of auditors and fixing or authorizing the Board to fix the remuneration of the auditor; and
(e) any other business that may be properly brought before the meeting.

4.02 - Special Meetings of Members
The directors may, from time to time, call a special meeting of the members of the Corporation. The directors shall call a special meeting of the members of the Corporation if at least ten percent (10%) of the voting members of the Corporation request that a special meeting be called.

4.03 - Place of Meetings
Meetings of the members shall be held at the head office of the Corporation or elsewhere as the executive or the president may, from time to time, determine.

4.04 - Notice of Meetings
(a) Notice of the annual general meeting shall be given to the members by the Secretary at least fifteen (15) days before the date of the annual meeting. Notice of a special meeting of members shall be given to the members by the secretary at least seven (7) days before the date of the meeting.
(b) Any notice required to be given under the by-laws or otherwise shall be deemed to have been given if it is:
(i) delivered personally to the person to whom it is given;
(ii) delivered to the person's address as recorded in the Corporation's records;

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(iii) mailed to the person's address as recorded in the Corporation's records by prepaid ordinary mail;
(iv) sent to the person's address as recorded in the Corporation's records by any means of transmittal or delivery (including facsimile and electronic mail).
A notice shall be deemed to have been given when it is delivered personally or to the person's address, or three (3) days after it was mailed or otherwise transmitted.
(c) The notice shall specify the business to be attended to at the annual general meeting or special meeting of members.

4.05 - Quorum
Quorum for the annual general meeting or for a special meeting of the Corporation shall be as follows:
(a) if the total voting membership is less than eighteen (18) members, quorum shall be one half (1/2) or six (6) members of the Corporation present in person, whichever is less, provided that at least two (2) voting members, other than directors, are present in person at the meeting; or
(b) if the total number of voting members of the Corporation equals eighteen (18) or more, quorum shall be one third (1/3rd) of the membership or ten (10) members of the Corporation present in person, whichever is less, provided that at least two (2) voting members, other than directors, are present and in person at the meeting.

4.06 - Chairperson and Secretary
The president or, in his or her absence, the vice-president, shall chair any meeting of members. If neither officer is present within fifteen (15) minutes from the time fixed for holding the meeting, the persons present and entitled to vote shall choose one (1) of the members to chair the meeting. The secretary of the Corporation shall be secretary of any meeting of members. If the secretary

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of the Corporation is absent, the chairperson shall appoint someone to act as secretary of the meeting.

4.07 - Voting

(a) Subject to Article 3.04 (c), each voting member is entitled to one (1) vote. The chair of the meeting is entitled to a casting vote in the event of a tie on any matter before that meeting that has been voted upon by the voting members.
(b) A vote at a meeting may be given by proxy in writing delivered to the secretary no later than forty-eight (48) hours prior to the meeting.
(c) A member shall not participate in the discussion nor vote on a motion or resolution with which he or she has a conflict of interest.

4.08 - Adjournment

Any meeting of the Corporation may be adjourned to any time and from time to time. No notice shall be required for any adjournment. An adjournment may be made with or without a quorum being present.

PART V - BOARD OF DIRECTORS

5.01 - Powers of Directors

The Board of Directors shall be responsible for:
(a) the overall direction of the Corporation;
(b) developing and approving policies of the Corporation; and
(c) managing and directing the affairs and property of the Corporation.

The directors may, on behalf of the Corporation, exercise all the powers that the Corporation may legally exercise under the Act, Letters Patent or otherwise, unless the directors are restricted by law or by the members from exercising those powers.

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5.02 - Number of Directors
The board shall endeavour to ensure that there are at least six (6) elected directors of the Corporation, and in any event there shall be no more than nine (9) elected directors. The immediate past president of the Corporation shall automatically be entitled to be a director of the Corporation.

5.03 - Qualifications
Each director shall be a member in good standing of the Corporation at least thirty (30) days prior to his or her election to the Board of Directors and shall remain a member in good standing throughout his or her term of office. A director shall be at least eighteen (18) years of age and shall not be an undischarged bankrupt person. A director shall not be an employee of the Corporation or of Guelph Services for the Autistic and shall not be a Lifesharer.

5.04 - Election of Directors
The election of directors shall take place at each annual general meeting of members. The directors shall be elected under the following conditions:
(a) Individuals who are members under paragraph (a) of Article 3.01 ("Active Members") shall each appoint one director, up to a maximum of four directors. In the event that the association has more than four Active Members, the Active Members will elect four members to the board
(b) The Immediate Past President shall be elected to the Board as a Director [replaces "as the ninth Director"]. Should the Past President choose not to sit as a Director, the Associate Members shall elect another Director in his or her place.
(c) Individuals who are admitted as members under paragraph (b) of Article 3.01 ("Associate Members") shall elect a number of directors consistent with section 5.02 and (a) and (b) above.

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5.05 - Term of Office
A director shall be elected for a two (2) year term and may sit on the Board of Directors for a maximum of six (6) consecutive years. An individual who has served on the Board of Directors for the maximum number of consecutive years shall be eligible for re-election to the Board on the same terms and conditions after a one (1) year absence. The board shall endeavour to ensure that the term of office of close to one-half of board members expires each year.

5.06 - Termination of Office
(a) The office of a director shall be terminated upon the occurrence of one of the following events:
(i) if the director fails to maintain the qualifications specified in Article 5.03;
(ii) if by notice in writing to the Corporation, the director resigns his or her office and such resignation is accepted by the Board by a simple majority vote; or
(iii) if at a special meeting of members, a resolution is passed by two-thirds of the votes cast by the members present at the meeting that the director be removed from office.
(b) The office of a director may be terminated by resolution of the Board if the director is absent for four (4) consecutive complete meetings of the Board of Directors.

5.07 - Vacancies
If a vacancy occurs on the Board, the remaining directors, if constituting a quorum, may appoint a qualified person to fill the vacancy until the next annual general meeting. In the absence of a quorum, the executive or president shall immediately call a special meeting of the members to fill the vacancy.

5.08 - Quorum

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A quorum for a meeting of the Board of Directors shall be three (3) of the directors.

5.09 - Meetings of the Directors

(a) Meetings of the Board may be called by the president, vice-president, the secretary or any two (2) members of the Board.

(b) No formal notice of any meeting of the Board shall be necessary if all the elected directors are present or if those absent have indicated their consent to the meeting being held in their absence.

(c) The Board may appoint a day or days in the month or months for regular meetings at an hour to be named. If regular meetings are scheduled, no additional notice is required. A meeting of directors may also take place without notice immediately after an annual general meeting or a special meeting of members to transact any business.

(d) No error or omission with respect to notice for a meeting of the Board shall invalidate the meeting or invalidate or make void any proceedings taken or had at the meeting.

(e) The president, or in his or her absence, the vice-president shall chair any meeting of the Board. If no such officer is present, the directors shall choose one of their number to chair the meeting. The Board may appoint a recording secretary, who is not a director, and who shall have no right to vote, to take the minutes of its meetings. Otherwise, the secretary of the Corporation shall act as secretary of the Board of Directors.

5.10 - Votes to Govern

(a) Subject to Article 5.10 (c), the directors shall vote on any resolution arising at any meeting of the Board. A majority of votes shall decide the resolution. In the case of a tie vote, the chair of the meeting shall have a casting vote in addition to his or her original vote.

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(b) A declaration by the secretary that a resolution has been carried and entry to that effect in the minutes shall be admissible in evidence as *prima facie* proof of the fact without proof of the number or proportion of the votes recorded in favour or against any resolution.
(c) A director shall not participate in the discussion nor vote on a motion or resolution with which he or she has a conflict of interest.

5.11 - Remuneration of Directors
The directors of the Corporation shall serve without remuneration and no director shall directly or indirectly receive any profits from his or her position as director. A director may be paid reasonable expenses incurred by him or her in the performance of his or her duties.

5.12 - Policy Development
Policies of the Corporation shall be developed or changed by the Board by resolution. At each annual general meeting, the Board shall advise the membership of all policies that have been approved or changed since the previous annual general meeting.

5.13 - Procedure
The business of the Board shall be conducted and dealt with in accordance with the most recent edition of *Robert's Rules of Order*.

5.14 -- Honorary Members of the Board of Directors.
From time to time the nominating committee may submit to the annual general meeting a motion to appoint people to the post of Honorary Member of the Board of Directors as recognition of their exemplary service to GSA. There shall be no limit on the number of people who can be so recognized, nor on their terms of appointment. Honorary members of the board shall be invited to attend

board meetings and to participate in discussions at the meetings, but they shall not have voting privileges by virtue of their position as honorary board members. An honorary member of the board can also become an elected member of the board under the provisions of section 5.04.

PART VI - OFFICERS

6.01 - Number of Officers

The officers of the Corporation shall be the president, vice-president, secretary, treasurer and past president. The positions of secretary and treasurer may be combined into one position where the directors consider it appropriate. Together these officers constitute the executive of the Corporation.

6.02 - Election and Term of Officers

The officers shall be elected by Board of Directors from amongst themselves each year at the first meeting of the Board of Directors following the annual general meeting. The officers shall serve until the next annual general meeting or until he or she resigns in writing or is removed from office by resolution of the Board of Directors. The term of office is one (1) year with a maximum of three (3) consecutive years in each office.

6.03 - Vacancies

If a vacancy occurs in any office, the Board, at its next meeting, may appoint a qualified person to fill the vacancy for the remainder of the term.

6.04 - Duties of Officers

The officers of the Corporation shall have the following duties:

(a) President - chair all meetings of the Corporation and of the Board, when present in person and able; have general supervision of the affairs of the

Corporation; sign all by-laws and execute any documents as may be required by these by-laws; perform any other duties which the Board may, from time to time, assign;

(b) Vice-President - exercise any or all the duties of the president in the absence of the president or if the president is unable for any reason to perform those duties; and perform any other duties which the Board may, from time to time, assign;

(c) Secretary - keep and maintain the records and books of the Corporation, including the registry of officers and directors, the registry of members, the minutes of the annual general meetings or special meetings and meetings of the Board, the by-laws and resolutions; have custody of the corporate seal; certify copies of any record, registry, by-law, resolution or minute; give notice as required for the annual general meeting, special meetings and meetings of the Board of Directors; and perform any other duties which the Board may, from time to time, assign; and

(d) Treasurer - keep and maintain the financial records and books of the Corporation; sign cheques or other documents as may be required under these by-laws; assist the auditor in the preparation of the financial statements of the Corporation; and perform any other duties which the Board may, from time to time, assign.

PART VII - BUSINESS OF THE CORPORATION

7.01 - Fiscal Year

The fiscal year of the Corporation shall end on December 31st of each year.

7.02 - Signing Officers

The Corporation shall have a minimum of three (3) signing officers who are Board members and one (1) of whom shall be the treasurer of the Corporation. In addition, the Board may appoint, as it sees fit, additional signing officers who are not directors. All contracts, obligations, transfers, cheques and other corporate documents may be signed on behalf of the Corporation by any two (2) officers, one of whom must be a director of the Corporation. The secretary of the Corporation may affix the corporate seal to any document that must be sealed.

7.03 - Banking Arrangements
The banking business of the Corporation shall be transacted with such banks, trust companies, or other financial institutions as may, from time to time, be designated by or under the authority of the Board. Any banking business shall be transacted with such agreements, instructions and delegations of power as the Board may, from time to time, prescribe or authorize.

7.04 - Auditors
Members of the annual general meeting shall appoint auditors for the Corporation to hold office during the next year following or until successors are appointed. The auditors so appointed shall either be certified accountants, or shall consist of a volunteer committee of members of the organization which does not include members of the board, so long as that is consistent with all legal requirements of the organization.

7.05 - Borrowing Powers
The Board may from time to time:
(a) borrow money on the credit of the Corporation by obtaining loans or advances or otherwise;
(b) issue, sell or pledge securities of the Corporation;

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(c) give a guarantee on behalf of the Corporation to secure the performance of an obligation of any person; and
(d) assign, transfer, convey, hypothecate, mortgage, pledge, charge or give security in any manner upon any or all of the real or personal, moveable or immoveable property rights, powers, choses in action, or other assets, present or future, of the Corporation to secure any such securities or other securities of the Corporation or any money borrowed or to be borrowed or any obligation or liabilities as aforesaid or otherwise of the Corporation heretofore, now, or hereafter made or incurred directly or indirectly or otherwise;
(e) delegate any or all of the foregoing powers from time to time to any one or more of the directors or officers of the Corporation as the Board considers appropriate;
provided that, except where the Corporation borrows on the security of its real or personal property, its borrowing power shall be limited to borrowing money for current operating expenses.

This clause shall remain in force and be binding upon the Corporation as regards any person acting upon the faith of a copy of this clause certified by the Secretary of the Corporation until such person has received written notification from the Corporation that this clause has been repealed or replaced.

7.06 - Agents and Employees
The Board may appoint any agents and retain any employees that it considers necessary. The persons appointed or retained shall have the authority and shall perform the duties prescribed by the Board. The remuneration for any agents or employees shall be approved by the Board by resolution.

PART VIII - COMMITTEES

8.01 - Nominating Committee

The Nominating Committee shall be a standing committee of the Board, and shall consist of at least two members, at least one of whom is a Director. The Nominating Committee shall, whenever possible, seek input of the active members during its deliberations. The Board shall appoint the Nominating Committee from year to year during the meeting at which the officers are elected. The Nominating Committee shall:

(a) advise the members at each annual general meeting with respect to suitable individuals for the Board of Directors;

(b) in advance of the Annual General Meeting, conduct a review of the skills and expertise required by the Board of Directors, solicit nominations of potential Board members from members of the corporation, prepare a slate for the Board of Directors, and notify the members of the corporation of the nominations;

(c) at least twenty (20) days prior to the annual general meeting ensure that the slate for the Board of Directors is completed and that all members are notified of the nominations;

(d) solicit any further nominations from the floor at the annual general meeting.

8.02 - Other Committees

The Board may, from time to time, appoint any other committee or committees that it considers necessary or appropriate. The Board shall, when appointing any committee, set out the purposes of the committee, its procedures and powers, provided that the committee shall not exercise any of the powers or carry out any duties that are legally required to be exercised or carried out by the Board of Directors.

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8.03 - Appointment of Chairpersons
The Nominating Committee shall make recommendations to the Board of Directors regarding the appointment of chairpersons of committees of the Corporation. The Board of Directors shall appoint chairpersons of committees by resolution.

8.04 - Additional Committee Members
Subject to Article 8.01, the chairperson of each committee shall add such additional members from within or without the Board of Directors as he or she considers advisable for the proper functioning of the committee.

8.05 - Procedure
Unless otherwise ordered by the Board, each committee shall have the power to fix its quorum and to regulate its procedure, including notice of meetings to its members, maintaining records of its meetings and reporting to the Board.

PART IX - INDEMNIFICATION
9.01 - Indemnification of Directors
The Corporation shall indemnify and save harmless the directors, their heirs, executors and administrators, and estates and effects, respectively from time to time and at all times from and against:
(a) all costs, charges and expenses whatsoever that he or she sustains or incurs or about any action, suit or proceeding that is brought, commenced or prosecuted against him or her, for or in respect of any act, deed, matter or thing whatsoever made, done or permitted by him or her in the execution of the duties of his or her office; and
(b) all other costs, charges and expenses that he or she sustains or incurs in or about or arising from or in relation to the affairs except costs, charges or expenses that are occasioned by his or her wilful neglect or default.

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PART X - ENACTMENT AND AMENDMENT OF GENERAL BY-LAWS

10.01 - Enactment of By-law

By-laws of the Corporation may be enacted, repealed, amended, altered, added to or re-enacted in the manner contemplated in, and subject to the provisions of, the Corporations Act.

10.02 - Repeal

Subject to the provisions of Sections 10.03 and 10.04 hereof, all prior by-laws, resolutions and other enactments of the Corporation heretofore enacted or made are repealed.

10.03 - Exception

The provisions of Section 10.02 shall not extend to any by-law or resolution heretofore enacted for the purpose of providing to the Board the power or authority to borrow.

10.04 - Proviso

Provided however that the repeal of prior by-laws, resolutions or other enactments shall not impair in any way the validity of any act or thing done pursuant to any such repealed by-law, resolution or other enactment.

PART XI - DISSOLUTION

11.01 - Requirements for Dissolution

The organization may be dissolved following four-fifths (4/5ths) vote of the votes cast by members at a meeting called specifically to consider a motion of dissolution. The membership shall receive sixty (60) days prior notice of any meeting to consider a motion of dissolution stating the purpose of the motion and the specific date, time and place of the meeting.

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11.02 - Winding Up and Disposition of Assets
Upon dissolution of the Corporation, any asset remaining after the payment and satisfaction of the debts and liabilities shall be transferred to an organization or organizations having cognate or similar objects which carry on their work solely in Canada.

PART XII - EFFECTIVE DATE
12.01 This by-law shall come into force without further formality upon its enactment.

PASSED by the Board of Directors and sealed with the corporate seal this .... day of ,..... in the year .....

_____
President

_____
Secretary

RATIFIED by the membership this ..... day of ..... , ...

_____
President

_____
Secretary

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GSA's Model Aroha Agreement

GSA relies on the Aroha entity of each active member to pay attention to and monitor all aspects of his quality of life and to be a party to agreements made by or with him. These relationships are discussed especially in Chapters 3 and 5. This model agreement should be adapted from person to person and also as a person's circumstances may change, especially when he may leave his family home for his own home and, later, after his parents can no longer support him.

THIS AGREEMENT made this _____ day of _____ (month) _____ (year) BETWEEN:

Guelph Services for the Autistic, (GSA) a non-profit charitable corporation, -and- **Adam Smith**, -and- **Friends of Adam Smith,** (FAS), an incorporated Aroha entity,

A. Terminology:

For the purposes of this document,

- *Adam* is Adam Smith
- *the family* is .....[names of parents or siblings or equivalent]
- *Friends of Adam Smith (FAS)* or *Adam's Aroha* is an incorporated not-for profit entity. Its directors now consist of Adam, his parents and three friends, who have voluntarily organized themselves as a group to safeguard and work for the interests of Adam. They are the core of Adam's larger circle of friends. FAS was incorporated in ..... [date], when Adam asked trusted friends to help him to

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manage the supports and services he needs for a good life in his community.

- *the housing agreement* is the agreement between Adam, the family and FAS, and GSA for the use of the property located at ..... [address] in Ontario. The housing agreement is intended to provide a home for Adam for his lifetime and to give him a lifetime right of occupancy in the property. By making this housing agreement with GSA, Adam is an "active member" of GSA.

- *the personal support agreement* is the agreement between Adam, his family, FAS, GSA, and transfer payment agency (TPA) to flow individualized funds to meet Adam's disability support costs.

B. Purposes:
The general purpose of Adam's Aroha is to support him co-ordinating and administering any and all resources for his good whole life, both now and in the longer term.

While Adam's parents still live, non-family directors of the Aroha:
1. Listen to him and keep informed of his dreams, evolving abilities and needs
2. Share time and interests with him
3. Make connections with new friends, resources and opportunities for learning and work
4. Be a party to any formal agreements such as: the housing/occupancy agreement with GSA; the personal support agreement with the TPA; and agreements with lifesharers, live-in caregivers, support workers and consultants
5. Be aware of policies and practices of the social service system that may affect him.

In the longer term, the Aroha directors would have more roles in supporting Adam to keep his good life going beyond his parents. The objects of

incorporation (Appendix 2) give them the powers to do so and Adam's parents have made legal and financial plans for the future which should sustain Adam's good life and make the Aroha's tasks as simple as possible. These include:

1. Ensuring that Adam has ways to understand options and to make decisions about his life, using whatever communication works for him and maintaining his supported decision-making agreement.
2. Ensuring that available resources and supports are used to maintain Adam's good life, including any or all of the following tasks, as needed from time to time:
    a) Receiving and accounting for funding directly from Government or through a Transfer Payment Agency, monitoring the relationship with the TPA, and advocating for increased funds when necessary
    b) Administering trust funds set up by family members
    c) Monitoring and maintaining Adam's occupancy agreement with his housing trust, Guelph Services for the Autistic.
    d) Making agreements and contracts with independent service providers and consultants
    e) Making agreements and contracts with facilitators and agencies that may provide services
    f) Acting as employer of record for support workers
    g) Monitoring the co-ordination and quality of Adam's whole life

In consideration of the above noted purposes and covenants, and for other valuable considerations the sufficiency of which is acknowledged, the parties agree as follows:

C: GSA recognizes:

1. The vital and necessary roles of Adam's Aroha in supporting his quality of life in general and enabling him to maintain his occupancy in the property (as outlined above).

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2. Adam's Aroha as a party to various formal agreements that support elements of Adam's life, including: the housing/occupancy agreement with GSA; the personal support agreement with the TPA; and agreements with lifesharers, live-in caregivers, support workers and consultants.
3. Adam's Aroha as an essential safeguard to sustain his good life in the longer term, when his parents can no longer support him—using the powers conferred by incorporation.
4. The directors of Adam's Aroha as honorary associate members and volunteers of GSA.
5. Friends of Adam Smith (FAS) as a related organization.

D: FAS undertakes:
1. To report regularly to GSA about Adam's evolving abilities and needs and the quality of his good life.
2. To do all within its powers to maintain his occupancy in his home.

D. Amendments
This agreement may be amended by mutual agreement among the parties. An amendment to this agreement shall not be valid unless it is in writing and properly executed by all parties.

SIGNED, SEALED AND DELIVERED by the parties hereto
this _____ day of _____, _____.

Adam _____

For FAS _____

For GSA _____

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GSA's Model Agreement with Family Lenders

The GSA model gives families the opportunity to invest capital and other resources so their son or daughter with a disability can live in their own home with the support of Aroha friends and with rights and means to express themselves and make their own choices. GSA offers to do all in its power to sustain the person's occupancy into the future, beyond the death of parents. GSA registers the amount contributed by a family as a Collateral Mortgage on the property and families are entitled to eventual repayment in various circumstances. This model agreement is discussed in Chapter 6.

This Agreement made as of the _____ day of _____, 2_____
BETWEEN:

_____, a charitable non profit corporation

(The "Corporation") AND-

_____, on joint account,

with right of survivorship (the "Lender")

WHEREAS:
1. The Corporation wishes to borrow moneys from time to time from the Lender; and
2. The indebtedness represented by such borrowing is to be secured by a collateral mortgage (the "Collateral Mortgage") registered in the real property

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owned by the Corporation and known municipally as

_____

NOW THEREFORE in consideration of the covenants and agreements herein contained and for other good and valuable consideration (the receipt and adequacy whereof is herein acknowledged) the parties hereto agree as follows:

1. Interpretation

1.01 **Definitions**. For the purposes of this Agreement and where the context does not otherwise require, the following terms shall have the following meanings:

(a) "Corporation" means _____[name of housing trust} and any successor corporation.

(b) "Indebtedness" means all principal and premium, if any, payable pursuant to the provisions of this Agreement from time to time outstanding and all other moneys for the time being and from time to time owing pursuant to the provisions hereof;

(c) "Lender" means _____[names of family lenders] on joint account with right of survivorship

(d) "Real Property" means the property municipally known as

_____

(e) "this Agreement", "hereto", "herein", "hereof", "hereby", "hereunder", and similar expressions refer to this Agreement and not to any particular

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paragraph or other portion hereof, and include any and every instrument supplemental and ancillary hereto or in implementation hereof.

1.02 **Plurality and Gender, etc.** Words importing the singular number shall include the plural and vice versa, and words importing the masculine gender shall include the feminine gender and the neuter gender.

1.03 **Headings.** The headings of the articles, paragraphs and sections hereof are inserted for convenience only and shall not affect the construction or interpretation of this Agreement.

1.04 **Applicable Law.** This Agreement shall be construed in accordance with the laws of the Province of Ontario.

2. Representations and Warranties

2.01 **Representations and warranties**

(1) Except as otherwise disclosed herein the Corporation hereby represents and warrants to the Lender and acknowledges that the Lender is relying on such representations and warranties in entering into this Agreement and in making advances of the funds provided hereunder to the Corporation, as follows:

(a) Status of corporation – The Corporation is a valid and subsisting corporation under the laws of its jurisdiction or incorporation and has full capacity and power to carry on its business and further has the power and is duly authorized to enter into, execute and deliver this Agreement.

(b) Violation of other instruments and authorization—

(i) The entering into of this Agreement by the Corporation does not conflict and will not conflict with, and does not result and will not result in a breach of the letters patent or the by-laws of the Corporation or any of the covenants

contained in any agreement to which the Corporation is a party or by which the Corporation is bound or to which any of its property is subject.

(ii) All corporate steps and proceedings necessary to authorize the entering to of this Agreement and all other security for the Indebtedness have been duly taken or held.

(c) Compliance with by-laws – The Corporation is not in breach of any by-laws, laws, statutes, regulations, rules or orders of any government or agency thereof which would materially impair its ability to carry on its mandate or materially affect the value of its assets.

(2) The foregoing representations and warranties shall be regarded for all purposes as having been made on each date on which the Lender advances funds pursuant to Section 3.01 hereof and shall survive each advance of funds pursuant to section 3.01 hereof and shall continue in full force and effect for the benefit of the Lender.

3. Advance of Funds

3.01 **Advance.** The Lender has or shall make available the loans provided for herein to the Corporation.

3.02 **Use of proceeds.** The Corporation shall use the proceeds of any advance made by the Lender pursuant to Section 3.01 hereof for the purposes of the mandate and objects of the Corporation.

4. Amount and Payment of Indebtedness

4.01 **Schedule A.** The principal from time to time outstanding hereunder shall be evidenced in Schedule A attached hereto, which may be amended from time to time by mutual agreement of the parties.

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4.02 **PROVISO.** Notwithstanding the amount(s) listed on Schedule A, in the Event of Default as herein described in Section 6 below, the Corporation shall owe to the Lender the greater of the total of the amounts listed on Schedule A or [.....per cent, depending on the amounts advanced] of the then current appraisal value of the Real Property.

5. General Covenants

5.01 **Covenants.**

The Corporation hereby covenants and agrees with the Lender that so long as any of the indebtedness remains unpaid:

(a) To maintain existence—The Corporation will at all times maintain its corporate existence.

(b) To insure its assets, and specifically the Real Property

(c) Further assurances—At any and all times the Corporation will, at its expense, do, execute, acknowledge and deliver or cause to be done, executed, acknowledged and delivered all and every such further acts, deeds, conveyances, mortgages, security agreements or instruments, transfers and assurances as the Lender shall reasonably require.

(d) To register—The Corporation will co-operate at its expense to the extent necessary to register the Collateral Mortgage without delay.

(e) Expenses of Lender—The Corporation shall pay all reasonable costs, charges and expenses (including legal fees and disbursement) of or incurred by the Lender in connection with this Agreement and all ancillary documents.

5.02 **Lender entitled to perform covenants** . If the Corporation shall fail to perform any covenant on its part herein contained, the Lender may, in its discretion, perform any such covenant capable of being performed by it and, if any such covenant requires the payment or expenditure of money, the Lender may make payments or expenditures with its own funds, or with money

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borrowed by or advanced to it for such purposes, but shall be under no obligation to do so; and all sums so expended or advanced shall be added to Schedule A hereto, and shall be payable out of any funds coming into the possession of the Lender in priority to the Indebtedness but no such performance or payment shall be deemed to relieve the Corporation from any default hereunder nor shall the right of the Lender under this subsection impose any obligation upon the Lender to perform any covenant of the Corporation.

6. Default and Enforcement

6.01 **Events of Default**. Each and every one of the following events shall constitute an event of default hereunder ("Event of Default"):

(a) if the Corporation shall neglect to carry out or observe any other covenant or condition herein contained on its part to be observed or performed and, after notice in writing has been given by or on behalf of the Lender to the corporation specifying such default and requiring that an end be put to the same, the Corporation shall fail to remedy such default within fifteen days of notification or, in the event that such default cannot reasonably be rectified within fifteen days (other than by reason of lack of moneys), then within a reasonable time given the particular circumstances, provided that the Corporation is diligently proceeding to remedy such default;

(b) if the Corporation ceases, or threatens to cease carrying on business or an order shall be made, or an effective resolution be passed by the Corporation for the winding-up, dissolution or liquidation of the Corporation;

(c) if the Corporation amalgamates with another organization or a transfer occurs so that there is a change in the control of the Corporation;

(d) if _____ [named person] no longer resides at the Real Property; and

(e) if the Corporation ceases to have or maintain control of the Real Property.

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6.02 **Acceleration on default.** Upon the occurrence of an Event of Default, the Lender may declare the Indebtedness to be due and payable and the Corporation shall pay to the Lender the Indebtedness pursuant to the provisions of Article 4 hereof, upon the sale of the Real Property or six (6) months within the declaration of an Event of Default, whichever is sooner.

6.03 **Remedies** Upon the occurrence of an Event of Default, the Lender may proceed to enforce its rights by any action, suit, remedy or proceedings authorized or permitted by law or by equity, may file such proofs of claim and other papers or documents as may be necessary or advisable in order to have its claims lodged in any bankruptcy, winding-up or other judicial proceeding relative to the Corporation or may enforce its rights under the Collateral Mortgage, all subject to time lines in 6.02 above.

7. Application of Funds on Realization of Security

7.01 **Application of funds.** Except as otherwise herein provided the moneys arising from any enforcement hereof and of the Security shall be applied as follows:

(a) firstly, in payment or reimbursement to the Lender of the reasonable expenses, disbursements and advances of the Lender (including the fees and expenses of any receiver or manager or receiver and manager or any similar person appointed in respect of the Corporation) incurred or made in connection with the enforcement hereof or of the Collateral Mortgage,

(b) secondly, in payment of the amount owing in accordance with Article 4 above, and

(c) thirdly, to pay the claims of any other person entitled thereto by law, and

(d) the surplus, if any, shall be paid to the Corporation.

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In the event that the proceeds of realization of the Collateral Mortgage are insufficient to pay the full amount of the Indebtedness, the Corporation shall remain liable for such deficiency

8. Notices

8.01 **Notices.**

(1) To the Corporation. Any notice sent to the Corporation shall be valid and effective if delivered to the Corporation or if sent by registered mail, postage prepaid or by facsimile, addressed to the Corporation at: [full address of the Corporation]

(2) To the Lender. Any notice sent to the Lender shall be valid and effective if delivered to the Lender or if sent by registered mail, postage prepaid, addressed to the Lender at: [full address of the Lender]

(3) **Deemed receipt**. Any notice given by mail shall be deemed to have been received on the fifth business day following the date of mailing unless delivery by mail is likely to be delayed by strike or slowdown of postal workers. Any notice which is delivered by hand shall be deemed to have been received on the date of such delivery if such date is a business day and such delivery was made during normal business hours; otherwise it shall be deemed to have been received on the business day next following such date of delivery. Any notice which is delivered by facsimile shall be deemed to have been received on the date of transmission if such date is a business day and such transmission was made during normal business hours; otherwise it shall be deemed to have been received on the business day next following such date of transmission.

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9. Miscellaneous

9.01. **Enurement and Assignment.** This Agreement shall enure to the benefit of and shall be binding upon the respective successors of the corporation and the Lender and may be assigned by the Lender, in whole or in part, in which event the Corporation shall attorn in all respects to such assignment and the assignee or assignees thereof.

In witness whereof the parties hereto have executed these presents under the hands of their proper officers in that behalf.

Date:
Named Corporation
Per:

_____

Officer. I have authority to bind the Corporation

_____

Signatures of Lender(s)

SCHEDULE A (set out and signed on following pages) states specific details of the Items of Indebtedness and effective dates.

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GSA's Model Occupancy/Housing Agreement (Sole Occupant)

FORMAL LEGAL VERSION

The occupancy agreement encapsulates the essence of GSA's function as a housing trust, in enabling a vulnerable person to live in her own home with dignity, respect and safety. It is the basic and central legal agreement between the housing trust and the person. Its various clauses enable the person named in the agreement to enjoy all the benefits of lifetime homeownership and to develop his home as the basis of a whole good life, while protected against the risks of exploitation or inadvertent failure to maintain occupancy.
Chapter 7 discusses this key agreement and includes the text of a plain-language version expressed in the first person. While the home is legally the property of GSA, which takes responsibility for its safety, maintenance and financial viability, everyone concerned regards it as the home of the person named in the agreement. Respect for each person who makes an occupancy agreement with GSA is also expressed in status as an "active member" and by the power to elect directors of the GSA board.

THIS AGREEMENT made this ____ day of _____, 2_____

BETWEEN: _____GUELPH SERVICES FOR THE AUTISTIC_____
a non profit charitable Ontario corporation (the "Housing Trust" or "GSA")
AND:

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_____

(name of focus person, supported by family members and Aroha)

1. THE PROPERTY

1.1 This Agreement sets out the rights and obligations of XX and the Housing Trust in property located at _____[street address] in

_____ [municipality] "the property"

2. GRANT OF OCCUPANCY

2.1 Subject to the other terms of this Agreement, the Housing Trust grants to XX a right to occupy the property for his lifetime.

2.2 The grant of occupancy to XX cannot be given to anyone else without the written permission of the Housing Trust.

2.3 XX does not have any other rights or interests in the property, except those that are stated in the Agreement.

2.4 XX shall always have his own bedroom and bathroom and the use of all parts of the home other than the private rooms of lifesharers.

2.5 XX's right to occupy the property will end when one of the events mentioned in Section 11 happens.

3. RENT

3.1 Subject to subsections 3.3 and 3.4, XX agrees to pay to the Housing Trust rent each month on the first day of every month. The first month's rent shall be paid on the first of the month that XX moves in. The rent shall be the rent

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portion of the ODSP or other amount arranged between XX and the Housing Trust. Rent does not include heat and utilities.

3.2 Subject to subsections 3.3. and 3.4, XX will receive sixty (60) days advance notice in writing of any change in the rent.

3.3 If XX receives the Ontario Disability Support Plan (or any successor income supports or benefits), the amount of rent payable by XX shall not exceed the maximum shelter component of that benefit.

3.4 If XX does not receive ODSP or other government benefits, or is receiving benefits that do not include a shelter component, the rent payable by XX shall not exceed forty percent (40%) of his monthly income.

4. <u>XX's RIGHTS AND RESPONSIBILITIES</u>

4.1 Subject to the other terms of this Agreement, XX will have the right to occupy the property for the rest of his life.

4.2 XX will be responsible for paying her rent on time.

4.3 XX will be responsible for paying his own telephone and cable television costs. These may be shared if XX shares the property with anyone else.

4.4 XX agrees to follow the occupancy rules that are attached to this Agreement.

4.5 XX agrees that he will not make any major changes to the inside or outside of the property without first getting written approval from the Housing

Trust. XX does not need the approval of the Housing Trust for painting or decorating the inside of the house.

4.6 XX will act responsibly and pay the Housing Trust for any damage he does to the property

4.7 Subject to subsection 5.3, XX agrees to help maintain the property and his share of cleaning, lawn and garden maintenance and snow and ice removal, and other minor maintenance.

4.8 XX shall be responsible for insuring his own and personal belongings against damage and theft. If XX cannot afford insurance, the Housing Trust will do it for him.

5. RIGHTS AND RESPONSIBILITIES OF THE HOUSING TRUST

5.1 The Housing Trust shall be responsible for keeping the property in good and safe condition and shall make repairs when they are necessary. The Housing Trust shall also make any changes to the property that are reasonable and necessary to ensure that XX can continue living in the property.
The Housing Trust shall talk to XX and to his parents and friends in his Aroha entity and ask for their comments prior to making any changes to the property.

5.2 The Housing Trust agrees to make sure that the heating and air conditioning systems are in good working order and are safe. If the heating or air conditioning system breaks down, the Housing Trust will also make sure that it is repaired as soon as possible

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5.3 If XX or other persons residing in the property are not able to maintain the property on their own (as stated in subsection 4.7), the Housing Trust shall ensure that the regular maintenance is done.

5.4 The Housing Trust shall be responsible for ensuring that functioning smoke detectors are places on every floor of the property that is occupied. The Housing Trust shall also be responsible for ensuring that a functioning fire extinguisher and a carbon monoxide detector are placed in the property.

5.5 The Housing Trust shall be responsible for ensuring that the property is insured.

6 RIGHT OF ENTRY

6.1 The Housing Trust, or people chosen by the Housing Trust, shall have the right to go into the property at reasonable times, to:

i. inspect or repair the property;
ii. maintain the property; or
iii. check on XX if there may be an emergency.

6.2 Members of the Aroha and circle of friends are welcome to visit XX at any time. Given his busy schedule, it is wise to check ahead with the lifesharers (or other co-ordinating supporters) that XX will be at home.

6.3 Notice to go into the property shall not be required where there may be an emergency.

7 TEMPORARY ABSENCE

7.1 XX may be absent from the property without terminating the grant of occupancy provided under this Agreement.

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7.2 During any temporary absence from the property, XX shall be responsible for paying his rent under this Agreement.

8 ABANDONMENT

8.1 Subject to subsection 8.3, if XX abandons the property, the Housing Trust back and offer a right of occupancy to someone else after sixty (60) days from the date of abandonment. Abandoning means leaving the property without giving notice of your plan to end the occupancy.

8.2 The Housing Trust will believe that XX has abandoned the property is most of XX's possessions have been removed and if XX owes rent to the Housing Trust.

8.3 The Housing Trust will make reasonable efforts to find out if XX intends to return to the property within sixty (60) days from the date of abandonment.

9 OTHER OCCUPANTS

9.1 During XX's term of occupancy, no other individual may be granted a right of occupancy in the property.

9.2 Other individuals may live in the property for the purposes of providing support and help to XX. Individuals who live in the property shall not have the same occupancy rights as XX.

10 TRANSFER OF OCCUPANCY

10.1 XX and the Housing Trust may, by mutual consent, transfer XX's right of occupancy to another property owned by the Housing Trust.

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10.2 Where, because of extenuating circumstances, XX decides that he needs to live elsewhere, the Housing Trust shall make all reasonable efforts to provide XX a right of occupancy in another property.

10.3 If XX transfers his right of occupancy to another property owned by the Housing Trust, the terms and conditions of this Agreement shall apply.

11 TRANSFER OF PROPERTY

11.1 If XX's circumstances require it, it may become necessary for the Housing Trust to transfer title to the property to another non-profit housing corporation. Any transfer of title shall not take place unless the Housing Trust and XX's parents/friends in XX's incorporated Aroha (or their legal representatives) are satisfied that XX will continue to have an enforceable right to occupy the property for his lifetime under an agreement in writing containing provisions similar to those in this Agreement.

11.2 The transfer of title to the property to another non-profit housing corporation will be a direct transfer without a sale price. The housing corporation taking title shall be responsible for paying any costs associated with the transfer.

12 END OF AGREEMENT

12.1 This Agreement may end for any one of the following reasons:

i. XX giving written notice of his plan to end the occupancy and the date on which his occupancy will end;
ii. Subject to subsection 12.2, XX's failure to pay his monthly rent;
iii. XX's abandonment of the property;
iv. The transfer of the title of the property pursuant to Section 11.
v. XX's death.

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12.2 The grant of occupancy shall not be terminated for failure to pay monthly rent unless the Housing Trust complies with all relevant provisions and provides all notices required under the Landlord and Tenant Act.

12.3 If XX is unable to express his plan to end the occupancy in writing, he shall be allowed to express his plan in another way of his choosing.

12.4 If XX tells the Housing Trust he wants to end his right to occupy the property, the Housing Trust shall verify XX's plan before ending the occupancy. The Housing Trust shall record, in writing, how and by whom XX's plan was verified.

13 ENFORCEABILITY

13.1 This Agreement shall be enforceable by and against the heirs, successors, assigns of XX and the Housing Trust and shall be subject to all federal and provincial laws that might apply in the Province of Ontario. This Agreement shall also be subject to all applicable municipal bylaws.

14 CANCELLATION

14.1 XX may, within five (5) days from the day he signs this agreement, talk with a friend or advocate and cancel this Agreement.

15 CHANGES TO THE AGREEMENT

This Agreement may be changed if XX and the Housing Trust agree to make the changes. Any changes to this Agreement shall not be valid unless it is in writing and properly signed by XX and the Housing Trust.

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16 VALIDATION OF THE AGREEMENT

16.1 This Agreement will be valid if XX signs it in any way that is usual for him.

16.2 The signatures of parents/directors of the Aroha entity are provided in support of XX's right of occupancy in the property. The Housing Trust acknowledges that XX's parents and directors of his Aroha entity are entitled to enforce this Agreement on behalf of XX and to protect his rights and interests. XX's parents are not liable for XX's obligations under this Agreement.

SIGNED, SEALED AND DELIVERED BY THE PARTIES hereto this ....day of

Date .....(month) ..... 2.... (year)

_____

XX signed

_____

_____

XX's parents/directors of Aroha entity

_____

_____

Two directors sign and apply seal of GUELPH SERVICES FOR THE AUTISTIC

A witness for each signatory also signs

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GSA's Model Lifesharing Agreement

Having one's own home can give an adult with a disability options for a valuable form of personal support. Lifesharers can be supportive friends and help with the tasks of daily living in return for sharing the home of a person with special needs--free or at a reduced cost. Lifesharers are inspired by the ideals of inclusion and intentional community in helping to meet the special needs of the people they are living with, and from the relationships that evolve between the various members of the household. In the GSA model, a lifesharer is neither an employee nor a tenant. A person with a disability who lives in his or her own home makes the choices about what happens in the home and does not have to move when a support relationship might have to end. Lifesharing is discussed in Chapter 8. Here we offer both a general agreement and a sample schedule itemizing what a particular lifesharing companion agrees to.

THIS AGREEMENT made this day of _____ _____
(month) (year)

BETWEEN:
Guelph Services for the Autistic, (*GSA*) a non-profit charitable corporation,
and **Alex Skelly**
and **Friends of Alex Skelly**
-and-
_____*(The lifesharer)*

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A. Terminology:
For the purposes of this document,

- *Alex* is Alex Skelly
- *the family* is Alex's parents _____
- *Friends of Alex Skelly (FAS)* is an incorporated Aroha entity whose directors consist of Alex and five others, who have voluntarily organized themselves as a group to safeguard and work for the interests of Alex. FAS is recognized by GSA as having a critical role in facilitating Alex's successful occupancy of the property.
- *the property* is the property located at _____
- *the housing agreement* is the agreement between Alex, the family, FAS and GSA for the use of the property.

B. Purpose:
Alex, the family, FAS and GSA have entered into the housing agreement, which is intended to provide a home for Alex for his lifetime.

The parties to this Lifesharer agreement acknowledge that under the terms of the housing agreement Alex has a lifetime right of occupancy in the property, and that he will require support and assistance to maintain such occupancy.

The purpose of this agreement is to contract to provide high quality residential support to Alex to enable him to maintain his occupancy within the property. *In consideration of the above noted purposes and covenants, and for other valuable considerations the sufficiency of which is acknowledged, the parties agree as follows:*

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1. Role of Lifesharer:

By entering into the agreement, the lifesharer agrees:

- To live co-operatively together in the property with Alex and any other lifesharers
- To provide residential support to Alex, as may be required, for the purposes of allowing him to remain living in the property, and to provide appropriate support, encouragement, assistance and supervision, as outlined in the Appendix.
- To fulfill the duties required for the smooth operation of the household as agreed with the FAS and any other lifesharers, as outlined in the Appendix.
- That the provisions in the Appendix will require review from time to time, and to meet with FAS from time to time to make adjustments to it as appropriate.
- That she/he is not a tenant, and shall not have any rights as such under any Residential Tenancy legislation, but will live in the home without paying rent, may contribute a monthly amount towards the cost of utilities and food, as described in the Appendix, and will pay for all long-distance telephone calls she/he makes.
- That she/he is not an employee of Alex, GSA, FAS, nor the family
- That the primary purpose of the property is to be the home of Alex, and so agrees that: if the relationship between the lifesharer and Alex does not work out, the lifesharer will move out within seven days of being asked in writing to do so by GSA, acting on the request of Alex, the family, or FAS.

2. Role of GSA

- GSA is the legal owner of the property, and agrees to be responsible for its financing, maintenance and insurance.

- GSA will make legal agreements with individuals who are selected by Alex, the family, and FAS to provide residential support to Alex so he can maintain his occupancy in the property (the lifesharers).
- GSA will enforce the terms of agreements with lifesharers, acting on the advice or at the wish of Alex, his parents or FAS. In particular, GSA acknowledges the right of Alex, his family, or FAS to instruct GSA to withdraw the residential support being provided by a specific lifesharer or lifesharers.
- If support cannot be provided by a resident lifesharer, GSA and FAS will make other support arrangements to ensure that Alex is able to maintain his occupancy in the property.
- GSA shall support the work of FAS in relation to the occupancy of the property to the extent that is practical for it to do so.

3. Role of FAS

FAS shall be responsible for:

- Working out an agreement with each lifesharer which makes clear the duties of that lifesharer both with respect to residential support and with respect to the smooth functioning of the living arrangements in the property
- Organizing the training of lifesharers in their residential support roles
- Organizing the ongoing support for lifesharers
- Ensuring that among the duties divided among the various lifesharers are those required for the keeping of appropriate household accounts
- Ensuring that GSA maintains the property properly in good repair
- Ensuring that there is open and appropriate communication between the lifesharers, Alex, the family, FAS and GSA.
- Reporting regularly to the board of GSA, and in particular seeking the agreement of GSA for major decisions it makes which are relevant to the

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role of GSA outlined in section 2.

- Meeting with lifesharers from time to time to adjust their duties as appropriate.

4. Term

The lifesharer shall begin to provide residential support on the date that she/he takes up residency in the property.

The first _____ month(s) from the date of the lifesharer taking up occupancy in the house shall be a trial period. Towards the end of this period, the lifesharer shall meet with Alex, the family, and FAS to evaluate the satisfactoriness of the arrangements to Alex and to the lifesharer. At this time, the details in the appendix may be adjusted, or either party may decide to terminate the arrangement by giving written notice.

GSA has a right to terminate this agreement:

- Immediately in the case of evidence or observation of any form of abuse
- Upon seven days notice to the lifesharer, upon the request of Alex, the family, or FAS, as provided in section 1
- Otherwise, with no less than thirty days written notice given to the lifesharer

The lifesharer can terminate this agreement with thirty days written notice, submitted to GSA.

7. Amendments

This agreement may be amended by mutual agreement among the parties. An amendment to this agreement shall not be valid unless it is in writing and properly executed by all parties.

SIGNED, SEALED AND DELIVERED by the parties hereto

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this _____ day of _____, _____.

Signed

Lifesharer _____

Alex _____

For FAS _____

For GSA _____

==========

See also following:
Appendix: Agreement on specific duties of this lifesharer, negotiated by FAS with Alex and the lifesharer

Schedule to Appendix 7
Sample Lifesharer Agreement with J-S
Benefits, Expectations and Specific Responsibilities

Benefits: J-S as lifesharing companion during the summer can help everyone.
Alex

- gets practice relating to a new companion in: making some meals and eating together; looking after himself, his dog and his home; and depending on others for help he needs;

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- looks forward to communication with someone who signs and is willing to use supported typing, and who can offer some shared and new leisure interests;
- knows that his dream of increasing independence in his own home is taking another step forward.

J-S

- shares a spacious home for the summer, with free room and board;
- gains unique learning and practical experience of an innovative form of support from the inside.

Alex's family, with FAS and GSA, know that Alex's plan and the GSA lifesharing model are moving ahead.

Expectations: Alex says "Good lifesharers, like friends, support me through what they are as well as what they do. I am looking for lifesharing friends who

- Respect me as a person who is smart and has thoughts and feelings
- Listen to me and share in my ways of communicating
- Understand what it's like to be me and what helps me to cope
- See that I try my best to help and contribute to other people too
- Support me to do all I can for myself rather than doing it all for me
- Share interests and abilities with me in some lasting ways, so I learn and practice more skills and leisure activities—such as cooking, music, gardening, hiking, my relationship with my dog, meeting new friends, some kinds of volunteering together."

J-S's Specific Responsibilities

1. Being proactive in building a good relationship with Alex
2. Accepting and co-operating with Alex's modes of communication including basic supported typing

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3. Attending to Alex's health (including diet, micronutrient supplements and sensory integration) and the safety of his home
4. Regular responsibility, three evenings a week, for making and sharing dinner with Alex, with cleanup, evening activities, bath and retiring routines. We suggest Tuesday, Wednesday and Thursday (including training Alex to sort and put out the garbage).
5. Sharing in family dinners all evenings she is at home here (we will have menus that are good for all tastes and sensitivities).
6. Keeping anchor lifesharer (or Alex's co-ordinator) informed of her schedule and, over dinner, one evening each week (such as Monday?), discussing how everything is going.
7. Recording her experience and helping us to connect with other possible lifesharers through the University and other volunteer networks
8. Co-operating in the smooth running of the whole household (as a responsible adult does in any home), including cleaning and care of her own room and the upper bathroom, doing her own laundry, and sharing in general care and cleanup of kitchen, living and common rooms.

In exchange, J-S receives free room and board and shared enjoyment of the amenities of Alex's home. She pays only for her special snacks and meals out, and for any personal use of Alex's phone for long-distance calls.

Signing this specific lifesharer agreement means that the parties seriously wish this arrangement to succeed. J-S knows of no factors that could interfere with her roles as a co-operative member of the household or as Alex's companion and supporter.

Signed and dated by all parties to the agreement

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Personal Support Agreement of Anthony Butler with His Aroha, Transfer Payment Agency (TPA), and Housing Trust (HT)

GSA's mission is to support adults with severe and complex autism who are very different from one another. When we shift our focus to presume competence, listen deeply and see a person's life from his point of view, it makes sense to think of support that is person-centred and self-directed. We know that the more complex the needs, the more individualized the supports must be. We must continue speaking up for and acting upon the principles of self-determination, citizenship, flexibility and ease of access to direct individualized funding, and ensuring safeguards through independent facilitation.

As GSA is an independent charitable corporation and not a transfer payment agency for the purposes of Ontario government funding, a special Personal Support Agreement was devised, to safeguard the quality of life of any active member of GSA and ensure accountability. This agreement is discussed in Chapter 9 which includes a plain-language version. The full legal agreement has an appended statement of Continuous Quality of Improvement which is a systematic guide for all who support a person in his good whole life.

This agreement concerns the use of funding provided by the Ontario Ministry of Community and Social Services [MCSS] to support the implementation of a

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personal living plan. The allocated funds for implementing this agreement are based on an annualized amount of $xxxxx. This amount may be adjusted and increased by further negotiation and planning and as approved by the MCSS.

Parties to the Agreement:

1. I, Anthony Butler [AB], a man who lives with complex challenges, have developed the foundations of a good life in my community. This agreement is expressed mainly from my point of view.

2. My Aroha [FAB, Friends of Anthony Butler], an incorporated entity of personal support formed of family members and friends, and the core of my circle of friends, with powers to receive and manage the supports I need to maintain a good life in the community.

3. [Transfer Payment Agency named, TPA] is recognized by the Ontario Ministry of Community and Social Services as a transfer payment agency for transferring funds to support persons with disabilities.

4. [Housing Trust named, HT], a not-for-profit charitable organization which functions as a housing trust to help adults and their families to implement personal support plans. HT owns and maintains my home and has made a legal agreement with me to recognize me as sole tenant for my lifetime or as long as I wish to live there.

5. Ontario Ministry of Community and Social Services [MCSS] through its XXX XXX Region administration.

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1. Responsibilities

a. Transfer Payment Agency named [TPA]

- *I, **Anthony Butler**, understand that [TPA] through your accountable mechanisms as a transfer payment agency, will:*
- Allow/enable/empower me (and all my caregivers, friends, Aroha entity, and any other direct service providers) to provide and co-ordinate the supports that I need to live in my home, enjoy the community and do my best;
- Act as a funding broker to facilitate the flow of MCSS funds as needed to support my direct services in my community, e.g., for housing, work and learning, health and nutrition, communication and social relationships, exercise and recreation, management of mood and movement disorders, personal support and encouragement;
- Receive support dollars provided on my behalf from the MCSS and account to the Regional Office on all expenditures up to the maximum amount approved;
- Maintain financial records of all expenditures authorized under the support agreement;
- TPA will supply monthly cheques in advance for 1/12 of the designated support dollars, the expenditure of which will be accounted for by FAB;
- Monitor and evaluate the quality of the support and assistance that is provided to me, using the standards and guidelines in my "Support Plan: Continuous Quality Improvement" and report back to me and my Aroha as well as the MCSS as required;
- Cooperate with the Regional Office of MCSS in assisting my Aroha successfully to implement my desire to live in the ways which have been expressed in my personal support plan.

- I, Anthony Butler, agree that:
- Transfer Payment Agency named [TPA] will not be responsible for any costs in excess of the approved level of funding provided to TPA by MCSS.

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- TPA is not expected to take responsibility for negotiating or justifying the appropriate level of funding to meet my needs or the requirements described in my personal plan.
- TPA will not assume any responsibility or liability whatsoever associated with the implementation of my home life or place of support. It is understood that full responsibility for the health, safety and security of my life will be assumed by me, by my Aroha and by the HT.
- If TPA takes on some obligations to me, to FAB, or to the HT beyond those outlined in this document and the time and cost of meeting its obligation therefore increases, negotiation of such administration costs will take place between TPA, my Aroha and MCSS.

b. Housing Trust (HT; a not-for-profit charitable corporation--Ontario Letters Patent XXXXXX)

I, Anthony Butler, want you to:

- Assist me in your capacity as a housing trust, to enable me to maintain my home and home life in the manner that I choose;
- Maintain ownership of my house and the responsibility of care and upkeep;
- Co-operate with my Aroha in meeting and reviewing the best ways to find people to share my house;
- Continue my lifelong occupancy agreement that was originally executed in XXXX
- Make legal agreements with individuals who are selected to share my home. I understand that these individuals may live in my home rent-free (or at reduced rent) and that you will undertake to protect my interests as best you are able to ensure that people I live with are neither tenants nor employed to support me;
- Indemnify TPA and the MCSS against any liability or risk arising from any occurrence or incident in the implementation of this agreement, including any

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liability relating to AB's employees or lifesharers, and satisfy TPA that the requirements of MCSS have been met and will continue to be met at all times with respect to conflicts of interest.

- **c. Anthony Butler in my Aroha (an incorporated not-for-profit entity for personal support; Ontario Letters Patent XXXXXX)**

- My Aroha will assist me directly by ensuring my well-being. Members of my Aroha will also ensure that I have opportunities for a positive and proactive role in planning, decision-making and efforts towards continuous quality improvements;

- We will recruit, select, support, direct and supervise my tutors, personal support workers as well as all relief, part-time and occasional staff. The staff who will be hired will understand my job expectations and will support me in achieving the outcomes listed below:

    - Each day needs to have a purpose and a routine that I am comfortable with

    - I will have meaningful and useful work, continued learning and exercise

    - I learn, and can be sure that the people working with me are helping me to learn, about the choices I have. In particular, I can choose the activities which interest me and can change them if I later decide that I don't like them

    - I will gain more independence in being able to communicate with people

    - I will achieve a sense of satisfaction with my life so I can manage the hard time better

- We will recruit, select, support, direct and supervise the people who agree to live with me;

- We will provide advice and other legal and financial information as required by the HT Board

- We will provide advice and any information needed to assist and enable TPA to fulfill its requirements under this agreement

- We will cooperate fully with TPA in meeting its responsibility under the terms of this agreement with the MCSS. We will provide all information needed by TPA to meet its statutory responsibilities and to maintain our mutual compliance with all relevant federal/provincial acts and regulations as well as the policies of the MCSS

- We will authorize TPA to receive all funds and process payments on my behalf as required

- We will review information provided by TPA concerning financial transactions made on my behalf and the amount of available funding remaining to me to implement the support plan within the funding/budget period. We will take appropriate action as necessary or recommended to ensure that we do not commit funding beyond our fiscal allocation.

- My Aroha will provide me with ongoing support with respect to personal and financial choices and actions in operating the household (and/or other) accounts for which the support cluster will be fully responsible. My Aroha will ensure that I am assisted to understand the choices that are available and to be able to express those choices in ways that are valid and reliable

- We will cooperate with TPA and the Regional Office of MCSS in the monitoring of continuous quality improvement (see attached statement). My Aroha will assist TPA in the administration of the checklist as needed

- We will establish and maintain all necessary connections with professional resources and consultants

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- We will have primary responsibility for advocating for my needs, including all activities concerning the budgetary process with the Regional Office of the MCSS

- We know that my Aroha and HT agree to indemnify the TPA and the MCSS against any liability arising from any occurrence or incident in the implementation of this agreement.

2. Self-Determination

All my service providers and informal support people will help me to make my own decisions. I have fundamental rights to make those decisions which affect how life unfolds daily. All service providers will offer encouragement, support and adequate opportunities in the process. My decision-making rights include but are not limited to: employment, education, personal goals, friends, the use of community amenities, leisure pursuits, the type of service being provided by the service provider and the manner in which the service is being provided. This includes choice in the people (paid and unpaid, formal and informal) who provide personal support, a role in describing job expectations, scheduling, supervising and evaluating staff.

3. Supports to Self-Determination

3.1 **My Aroha is my support circle of my family and friends.** They are people in my life who provide friendship, counsel and support in the decision-making process and assistance in monitoring service quality. They are involved in various aspects of my life and help me to meet new people in the community.

3.2 **My Key Contact is the person who can be called to talk about me**. XXXX XXXX will sign along with me so I have support to understand the nature and purpose of this document. In this supportive decision-making process, she

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will consider what she knows about me and how she observes and records my communications through supported typing and in other ways. She will also work with other family members and friends in my Aroha entity for personal support to ensure continuity.

3.3 **XXXXX XXXXXX is president of my Aroha and my planner/broker** who will act on my behalf and with other directors of the Aroha in planning, negotiating funding necessary to achieve the objectives of the plan, supporting me and the Aroha to review and monitor the success of the plan, adjusting the plan if necessary. XXXXX is the designated person to be recognized by all parties with respect to budget negotiation with the MCSS.

4. Individualized Funding

An individualized approach to funding is a tool to ensure an individualized range of supports and services. It is understood by all parties that the allocated dollars are to be used in supporting me to fulfill the objectives of my plan. Portability and flexibility are important features. Portability means that, if this agreement is terminated because of dissatisfaction, the allocated funds may be applied toward a new agreement with another service provider of my choice.

5. Flexibility

Recognizing that the need for support may fluctuate during this agreement, it is understood that the allocated funding will be flexible to enable necessary adjustments.

In the event that the allocated funds are not fully used during the terms of the contract, the following may be negotiated:

a) with the agreement of all parties, the present agreement may be extended;

b) a new agreement may be drawn up with this service provider or with another service provider subject to negotiation with the funder;

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c) if neither of the above is done, the unused funds will be used to support another person.

6. Monitoring

You TPA, I and my Aroha will be watching to make sure I'm getting what I asked for, as described in my personal plan and enabling maximum self-determination. We will also monitor service quality through the use of a quality assurance checklist and other procedures for continuous quality improvement and by taking part in periodic reviews of the supports and services being provided.

6.1 Changes to this agreement must be in writing and signed by all parties.
6.2 Anything written down about me is mine and I can read it when I want. Service providers will keep and make available to me upon request, information and particulars about their responsibilities, e.g. housing, financial and employee information. All documentation will be respectful of me and focus on capacities. Personal records will be kept at my home unless I ask otherwise.
6.3 TPA, with its legal and financial responsibilities for this agreement, keeps a copy of this agreement on file and proper accounts, records and receipts of all income and expenses related to this agreement for audit purposes, and these records are the property of TPA.
6.4 TPA will receive invoices from my Aroha through my key contact and provide written statements monthly.
6.5 If we disagree about something, we will talk to each other about it in a timely and effective manner. We will make every effort to resolve issues and disagreements on an informal basis as they arise. If an issue cannot be resolved in this manner, we will seek mediating support in a form on which we agree.

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7. My Rights and Responsibilities

I will make my own choices and you will respect them. I have the same human rights as everyone else under the Canadian Charter of Rights and Freedoms and the Ontario Human Rights Code. I will tell you honestly how I feel about the support you are giving me.

8. Review of Agreement

We agree to review this document and the budget within 12 months, and to look at outcomes and successes and financial information in relation to meeting my needs according to the terms of my personal plan and lifestyle choice. Any mutually agreed upon revisions will be made at this time.

7. Termination of Agreement

If you or I want to end this agreement, we can give two months' notice, or some other term of notice if we agree in writing.

These papers have been explained to me in a way I understand and I agree with everything said in these papers.

Signed and dated by:

AB

Aroha Representative

HT: Housing Trust Representative

TPA: Transfer Payment Agency Representative

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Schedule
Anthony's Support Plan:
Continuous Quality Improvement

original [date], updated at intervals to [date]

SUMMARY

My plan, first presented in ------, has several crucial and interrelated parts:

- Opportunities to make informed choices about my own life and to feel control and responsibility
- Friends who understand and believe in me, organized as a circle/cluster the core of which is my Aroha entity for personal support
- A regular, structured and well-co-ordinated pattern of activities including learning, work, recreation and community experience with both formal and informal people
- Recognition of my profound challenges in health, communication and adaptive functioning and the need for access to expert consultants for me and my support team
- Living in my own home with people I choose--in health and safety, and with a high quality of life and personal fulfilment
- Responsible use of resources, including accountability for public funds and for my well-being and quality of life.

To implement this plan, I with my support circle, now incorporated as an Aroha, first made an agreement in [date] with the transfer payment agency [TPA] recognized by the Ministry of Community and Social Services (MCSS), for the purpose of flowing funds to my support plan. HT, the non-profit charitable corporation that owns my home in trust for my lifelong occupancy, is also a partner in this agreement.

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We have learned so much together as pioneers. At my request, my support circle of family and friends has been incorporated as an Aroha entity for personal support which becomes a corporate partner in any personal support agreement.

To be fully sustainable, my personalized plan may require a more adequate budget--as proposed with the original plan. My Aroha will continue to advocate for such a budget while being creative with the available resources.

My plan is distinctive for being person-centred and self-directed. I know that I inspire others by showing how a person with quite severe disabilities can be supported to live a good life in the community, relating to people who are not defined by their disabilities, and having a wider range of friends than those who are paid to be with me. But all this is not easy: there are no detailed charts or blueprints. For my sake, and as a guide to others who would like to implement similar individualized plans, my support team has pledged various methods of quality assurance and continuous quality improvement. Outlined here in plain language, they are all attainable if we have imagination, faith and patience.

Goals and Strategies of Quality Assurance and Improvement

Quality assurance goals and methods must be proactive, positive and continuously reviewed for four main reasons:

a) The TPA is accountable for the proper use of public subsidy funds flowing to my personal support. Others involved in implementing my plan must keep proper records and report regularly to the TPA through the key contact who is secretary of the Aroha.

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b) The HT, the charitable non-profit corporation that functions as my housing trust, must report annually to Canada Revenue Agency on the proper use of its funds.

c) [Aroha], incorporated in [date] by me, my parents and core members of my circle of friends, is accountable for its management of the resources that are meant to support me. Above all, those who know me need procedures and checks to ensure that all the plans, funds and efforts are really being co-ordinated to benefit me. While this may seem self-evident, we need policies and procedures to ensure real accountability for me as I do not speak with my voice, and to protect me from abuse or neglect.

d) In concepts and implementation, my plan has innovative features that may be useful to other vulnerable adults and their families. So we document goals, objectives, strategies, responsibilities and outcomes, as well as the ways we address and solve new challenges.

Significant people and organizations, involved in implementing my plan, share its values, goals, objectives, strategies and safeguards:

(i) I, **Anthony,** take seriously my central role in understanding my options and making choices and decisions about any aspect of my life and the people who support me.

(ii) My incorporated Aroha [name]**,** formerly called my **circle or cluster**, has a crucial role in ensuring that my plan works to benefit me in real support and quality of life. Directors of my Aroha have joint corporate responsibility but also specific roles. XXX XXX, formerly advocate/broker for my plan and liaison with the Ministry in advocacy and negotiation for budgets, improved services and general

co-ordination, continues these roles as president of the Aroha. The vice-president has special responsibility for overseeing the physical safety and integrity of the house and property. The secretary-treasurer (and general manager) has key roles. Individual directors have special roles with my supported decision-making and personal quality of life, finding and mentoring people to be lifesharers and support workers, and ensuring that the members of my household form a harmonious community that shares the values of my support plan.

(iii) HT owns and maintains my home in trust for my lifelong occupancy, and carries liability insurance covering the implementation of my personal support plan.

(iv) My **lifesharers**, whom I have a key role in choosing, provide me with care, companionship and support in return for rent-free accommodation. Several compatible and responsible adults are needed to share the various roles of supporting me and maintaining a safe, healthy and satisfying lifestyle for the whole household. One major role for one or two lifesharers is to look out for my rights, well-being and quality of life in the household. Another role is that of health, safety and security officer for the household. A third role, probably shared between two lifesharers, is that of bursar, looking after supplies and accounts. Lifesharers with these roles report and relate to directors of the Aroha and the HT.

(vi) The Aroha, taking its lead from me, makes contracts with **several tutors and support workers, and with professional experts** who consult in the areas of augmentative and supported communication, diet and nutrition, sensory integration, anxiety and behaviour management, community inclusion, and independence technologies.

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(vii) TPA has assumed the role of transfer payment agency to flow individualized subsidy funds to support my plan. XXX XXX, secretary-treasurer of my Aroha, is designated key contact in relating to the TPA and reporting on behalf of my support team.

The most important evidence of quality in implementing my plan is that I am content and healthy and feel satisfaction with my quality of life and range of activities and relationships. Four of the six goals of quality assurance and improvement are concerned directly with my well-being and are considered first. For each goal, we outline strategies, persons responsible and specific quality assurance checks. We add a summary of the records that will be kept and checks that will be made by my lifesharers, my Aroha and the HT.

GOAL I: I am encouraged and stimulated by all effective strategies towards greater exercise of initiative and choice and to feel a sense of control over my life.

I have rights to choose and comment about the people in my immediate support team, and the activities and emphases of my daily and weekly timetables. This major goal cannot be achieved by vague goodwill and wishful thinking, but requires untiring patience and imagination by the people close to me. The following strategies are designed as vital safeguards against the kinds of abuse or neglect that can occur with a trusting person who does not speak.

Persons Responsible

Co-ordinated by the key contact person for my plan, in conjunction with the lifesharer(s) and Aroha members who take particular responsibility for my well-being. Other members of my support cluster meet individually with me to facilitate my understanding of important options and my expression of my

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preferences and other comments. We regularly consult with communication specialists.

Strategies:

1. My various communication methods are used consistently and integrally in the various areas of my life by people I know and trust and who will keep informed of best practices.

2. I am fully informed in advance about choices of all kinds and will be involved in planning my timetables of activities.

3. For critical decisions, three people close to me have special roles in ensuring that I am informed about my options, can make choices, and am satisfied with my life in its various aspects. This strategy has the following stages and be used on the eve of important decisions and routinely.

a) With my agreement, questions are carefully defined for me to consider and answer, several days before the events described in (b) below, so I have time to consider important choices after I have been helped to understand them. It helps me if the choices and questions are expressed in various ways, e.g., written out and illustrated as well as spoken about, and spread through several conversations.

b) At least three of my friends arrange times and shared activities with me in settings or environments where we have optimal rapport. We also agree on the most reliable modes of communication.

c) When I meet with each communication partner, the critical questions are put to me in the context of some shared and enjoyable activity in which we are relaxed and at ease with each other. My communication partners record my answers and comments and later compare notes and share their findings with significant others in my life. Others who have used this strategy report remarkable consistency of choices and responses.

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d) Any necessary changes are made in my timetable, activities or support people.

4. I have regular opportunities weekly to express my feelings and degree of satisfaction with the way my life is organized. My communication partners for these occasions include people not personally involved in my everyday activities and relationships.

Quality Assurance Checks

a) Records of my communications--daily, weekly and monthly--including topics and questions, partners and modes, and my messages, and how these were shared among lifesharers, teaching and other support people, and my Aroha group.

b) Minutes of discussions of significant findings that indicate need for changes in how to support me, and of the actions taken.

c) These records, with my permission and appropriately generalized, may be shared with the partners in my plan--including Aroha, other support circle members, HT and TPA.

GOAL II: I gain a widening range of friends with whom to share interests and relationships that give more meaning to my life (and probably to their lives too).

I know friends are the most important positive factor in my life—my lifeline, safety net and the "bridge from my island to the mainland."

Persons Responsible

Creative ideas from my whole circle of friends are pooled by the lifesharer(s) and Aroha/support cluster member(s) who take responsibility for my well-being. Advice, resources and timetable co-ordinated through key contact.

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Strategies

1. Continuous and imaginative efforts to foster friendships with new community people--especially through my friends and lifesharers, contacts in my neighbourhood, people for whom I work as a volunteer. While it is recognized that some of my circle of friends find it easier to help me through meetings, phone calls and paperwork of advocacy--all valuable and vital—I really need more personal contacts with individual friends or small groups.

2. Finding new friends with similar interests (exercise such as swimming and workouts, walking my dogs, music, books, puzzles and games, farms and outdoor work, my computer, trips and outings including special events and meals in restaurants).

3. Some features of my house attract friends--including the model railway, the piano, the naturalized garden and greenhouse, and the nearby parklands.

4. New friends may find it easier to include and relate to me in small groups.

5. New friendships should, as much as possible, not need to include my parents--so that I have scope to grow, and to decrease my dependence on them.

Quality Assurance Checks

Records kept daily and reviewed monthly, noting frequencies of meeting and size of group, and distinguishing formal and informal people and relationships which do not depend on parents.

GOAL III: My daily, weekly and monthly timetables include a balanced structure of continued learning, work (household, paid and volunteer), exercise and community experience. There is a balance

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between skills which are already well known (and might become more independent) and new skills that have to be patiently learned.
I clearly state the importance of the various activities of my daily life. I have sensible ideas about the varied kinds of work I want to do, which work should be paid for, and why we work. I want to continue learning, and I know how important exercise is for me. I like to work and exercise with men. I do much better when I know in advance the structure or timetable of a day or a week—but I can manage occasional pleasant surprises. Regular timetables may be modified in detail depending on weather conditions (such as high temperatures) or my mood and movement problems when I can manage to practise familiar skills but find it impossible to focus on learning new skills. In choosing skills in which I might try to be more independent, we give priority to those that have to be done every day and those for which I do not need others for non-work reasons such as transportation.

Persons Responsible
Key contact co-ordinates timetables and priorities with me, and advises the lifesharer and the Aroha member who take particular responsibility for my well-being. Professional advice, e.g., occupational therapy consultants.

Strategies
1. In drawing up timetables with my participation, there is a daily and weekly balance in activities--between those based at my home and out in the community, indoor and outdoor, sedentary and more active, and also between learning new skills and practising those that are already well known.

2. I continue to be able to learn about the range of possible activities, and to be introduced with support to new activities in which I express interest.

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3. I am informed and questioned about my preferences and priorities in activities by the methods outlined in I above, and changes I consistently request are respected.

4. I am encouraged and supported to develop increasing independence and initiative in various skills and daily living activities. My degree of independence in various current skills and activities is assessed, to provide a benchmark for discussing those in which I might learn to do more for myself. Part of learning to become more independent may be getting used to support from a different person (from a primary support person to another paid support person or to a volunteer), from which the step to even more initiative might be taken. In any case, learning to adapt to other companions is prudent in case of staff change.

Quality Assurance Checks

a) Timetables compiled and revised as necessary to show the balance of activities

b) Assessments of skill levels, compared over time. Records of efforts to attain more independence and results in maintaining skills levels or making gains great and small.

c) My communications about this major part of my life.

GOAL IV: My individualized support plan matches my very significant health and communication needs which must be recognized. I and my support team require access to the advice of expert professional consultants.

i. Moderately severely disabled by autism all my life, I do not speak with my voice though my receptive language is fairly good and I try hard to become proficient in alternative and augmentative systems. I am very expressive with supported typing, and also love to copy-type independently for several hours at a time.

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ii. At some times especially, my brain and central nervous system are noticeably slow in processing information coming in from my senses.

iii. I seem hypersensitive to all sensory stimuli, reacting particularly to changes in weather, temperature and pressure. In my thirties, I have experienced intermittently various neurological problems with mobility and sensitivity to touch of all kinds, being disabled in ways not previously detected. My friends observe a roughly cyclical pattern--though this is now less clear than earlier in the 1990s--in which I may be perpetually hyperactive for a stretch and then locked in frozen immobility at other times. Such cyclical patterns may be expressed in and are certainly exacerbated by sleep disturbances. I can be very tense indeed, and have bad headaches. My blood pressure and hear rate can go up and down .Since the age of 30, I have had grand mal seizures, now averaging one every two months.

iv. I have food sensitivities or intolerances--notably to all gluten, casein and sugar in any form or trace--and show paradoxical reactions to all drugs. I respond well to my special diet which uses basic organic food ingredients, and from several micronutrient supplements prescribed by my health professionals.

v. Perhaps because of my hypersensitivity to touch and texture, and fear of new situations, I strongly resist wearing new clothes and tolerate only a very narrow range of garments.

vi. For the same reasons and through my past experiences, I dislike visiting and being examined by doctors, dentists etc, even barbers, or giving blood. Because of this resistance and my paradoxical reactions to drugs, I do not use funded medicare services. What I reveal through my supported typing and what my closest supporters observe and record becomes highly relevant--either for explaining to health professionals or in indicating helpful remedies and strategies.

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Persons Responsible

Lifesharers and Aroha members are especially responsible for my well-being and the health, safety and well-being of my household:
-co-ordinating records kept by all people around me
-seeking and sharing advice from my physician, consultant dietician and other professionals
-relating to my communication partners for discussions with me about my health

Strategies

1. With respect for my privacy, I and the people close to me continue to keep daily records of how I feel, noting any factors (weather changes, sleep disturbances, changes in my companions or program of activities) that may trigger disturbances in my state of mind or body. These records are reviewed weekly and monthly, to detect patterns of possibly troublesome factors as well as those factors that seem to reduce or offset the worst stress for me.

2. My communication partners continue to plan weekly and daily timetables with me, and through social stories help to prepare me for any predictable changes in weather, companions and routines.

3. My special diet is maintained with nutritious and interesting meals that I help to prepare.

4. Daily relaxation exercises are continued, with the intent that I can continue these and call upon them at times of stress. I do yoga at least twice a week, a personal fitness trainer visits twice a week, and I have Reflexology treatments every other week.

5. Contact is maintained with professionals and specialists in fields that may help me. Advice from these people may need to be blended and tailored to my unique needs. One example is in helping me to accept and wear a wider range of clothing-

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-a challenge that may need a combination of sensory integration, communication and relaxation techniques.

6. Strategies for crisis intervention and backup are needed for the rare times (less frequently than once a year) when I cannot contain and control the stress in mind and body. Strategies must be gentle, respectful, safe for everyone, and effective in calming and reassuring me so I can relax. These may include offering me:
-the means of expressing myself (especially with supported typing)
-drinks of cold water and applications of cold facecloths at pressure points
-special classical music and soothing words about how my friends understand that it's all too much for me just now, but it will pass and I'll feel better, and be able to sleep etc
-encouragement to rest under my weighted blanket
During the years in my own home, I have learned to feel any signs of restlessness and can often suggest to others that I need one of these gentle strategies. My supporters can also read the signs and help me to control myself by one of these strategies. They may see warning signs of an approaching crisis and take avoiding action. Drugs do <u>not</u> help at all, as they prolong and intensify the crisis for days or weeks. Nor does meeting any sign of acting out with harsh words or physical restraint.

<u>Quality Assurance Checks</u>
a) Records kept and graphed of my mood balance, contentment and ability to function, with indications of likely factors, both positive and negative.

b) Evidence of support with my involvement in planning and carrying through a balanced timetable of activities.

c) Evidence of balanced and nutritious diet and relaxed and pleasant household dinner meal-times;

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d) Daily records of my weight, and blood pressure and pulse readings three times daily.

e) Notes of contacts with relevant professionals.

f) Evidence of crisis intervention strategies.

g) Monthly review of my total health and well-being, considering stressful and helpful factors

h) Annual physical exam, screening and immunization by medical practitioner; annual dental exam encouraged, but I have the right to refuse.

GOAL V: My home, shared with the people I choose, is a safe and satisfying living environment for all

Persons Responsible

Lifesharer who is household's health and safety officer (or deputy, if that person is absent) is responsible for making and recording daily and weekly checks and tests. Consults with Housing Trust director responsible for house safety and maintenance, who reports to each HT Board meeting.

Strategies and Quality Assurance Checks

1. All safety devices and procedures to protect my household against dangers of fire, burns, smoke inhalation or intrusion will be checked and tested regularly. These include:

-smoke detectors, carbon monoxide detectors, fire extinguishers, and emergency first aid kits on every level (tested monthly and serviced annually)
-exits and evacuation procedures in case of fire or other emergency (monthly)
-Fire Department inspection of property
-indoor air temperature (several times daily)
-hot-water temperatures set at maximum of 120 degrees Fahrenheit

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-storage of hazardous materials of any kind
-emergency lighting to come on in power outage
-door locks and keys (daily checks, with locking up routine last thing at night)
-no smoking policy inside the house

2. At all times, someone is particularly responsible for my physical safety and general well-being (lifesharers taking this in turns at nights), with alternative backup procedures as well.

3. I discuss safety concerns and procedures (he is already sensibly cautious about water temperatures, rangetop hotplates etc.)

GOAL VI: Household, subsidy and personal accounts are kept responsibly

I am rich in my friends, my spacious home, and my imaginative plan with its high quality of life. But these are intended to compensate and plan for a present and future in which I am cash-poor and have no family except for my parents. My pension income goes to pay my monthly rent and utilities. My special diet and supplements cost about five times the average dietary costs of other people. I also need special equipment and services for communication, special exercise, continued learning, transportation and my service dog.

Accounts

Financial accountability is maintained through three main accounts: the household account used for food, utilities and small contingencies; my personal living account (with a small balance for pocket money after rent and household contributions are paid); and the account for funds for my disability support funds flowed through the TPA.

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Strategies

1. Household accounts are kept by my anchor lifesharer who acts as bursar and is responsible for receiving and paying utility bills and meeting costs of all shared food and other household consumables and small contingencies and repairs.

2. I operate my personal account for ODSP income, supported by my key contact.

3. With other officers of my Aroha, I am a signatory for the disability support account for funds remitted from the TPA. Records of this account in particular are summarized monthly for the TPA.

4. Accounts are balanced monthly, and any trends noted and shared with others responsible for my well-being and that of my household.

Signed and dated (with details of dates of review and any revision) by:

AB

Aroha Representative

HT: Housing Trust Representative

TPA: Transfer Payment Agency Representative

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Glossary

Term or abbreviation	*Literal meaning*	*Explanation*
AAC	Alternative and augmentative communication	Communication systems (often using computerized devices) to help reliable self-expression by people who cannot use their voices because of neuromotor disorders, including adults with severe autism.
Agency	Social service agency or transfer payment agency	Incorporated service organization funded by Government to provide services by staff to clients.
Aroha	Incorporated entity of personal support	Formal and legal core of a circle of friends, with values and powers like a microboard's, to co-ordinate and sustain a good whole life for a person who is vulnerable because of disability. A necessary part of the GSA model.
ASD	Autism Spectrum Disorders	Term used from 1993-4 *(Diagnostic and Statistical Manual of Mental Disorders 4)* to include Autistic Disorder and Asperger's Disorder. For the new DSM5 classification and criteria (in effect from May 2013) see: http://www.dsm5.org/ProposedRevision/Pages/proposedrevision.aspx?rid=94
Autism ("Classic")	Autistic Disorder aka Kanner's Syndrome	More severe form of autism, first identified by psychiatrist Leo Kanner in 1943, that shows all the diagnostic features of ASD, sometime combined with other challenges such as epilepsy and hypersensitivities.

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ASPIRE	Autism Support Project: Information, Resources, Empowerment	Project of GSA from 2002 to 2005, to encourage persons and families living with autism to plan ahead for good lives and personal support networks.
Bridges	Bridges-Over-Barriers	A self-advocates' support group of adults who use supported typing and other AAC methods to express their thoughts and feelings. Sheltered by GSA from 2005.
Brokerage	Brokerage of personal supports	Unencumbered service pioneered in Windsor-Essex from 1990s to help vulnerable persons and families to plan, access and co-ordinate appropriate supports for each person.
Cohousing		People who choose to live close together and share common amenities as well as each other's company. Each person might have a self-contained suite or apartment. GSA might shelter such a project. May share ideals of intentional community
Develop-mental Services	Division of the Ontario Ministry of Community & Social Services	From 2011, responsible for assessing eligibility and funding services for adults in Ontario who have a developmental disability.
Direct funding	Payment of disability support funding direct to eligible individual or their representatives, with accountability safeguards.	Option (limited as yet) for person with family/Aroha to receive support dollars to be used as the person decides with self-directed planning, rather than through a Transfer Payment Agency that might operate group programs. Appropriate for adults with high support needs. Also known as Individualized Funding.

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GSA	Guelph Services for the Autistic	Incorporated 1980; now a housing trust helping families to plan and invest in individual homes where their adults with autism can live for as long as they need.
IF	Individualized Funding	Concept of funding individual persons with developmental disabilities, based on assessment of their needs and abilities, in contrast to block funding of agencies. Aka Direct Funding.
IFCO	Individualized Funding Coalition for Ontario	Collaborative working group of Ontario people and organizations pledged to change provincial policy to allow IF funding with self-directed planning and family involvement to become an option.
IF&P	Independent Facilitation & Planning	Support provided to persons and families for self-directed planning based on needs and gifts and for implementations of such plans. Independent of agencies providing clients with direct services. Similar to brokerage.
IRM	Innovative/ Individualized Residential Model	Pilot project by Ontario MCSS 2007-2009 to "create individually tailored living spaces" sometimes with family resources for the housing, with support dollars for workers flowed through agencies. See pp.27, 188.
Lifesharer		An individual who lives in property owned by the housing trust for the purpose of providing support or companionship to an individual who is a GSA active member.
MCSS	(Ontario) Ministry of Community and Social Services	Government ministry responsible for setting policy for developmental services. Source of funds that may be received by adults with

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		autism or other developmental disabilities, such as ODSP, SSAH and Passport, and of block funding to agencies for group programs.
Microboard		Self-directed supported corporation, first created in Manitoba in mid-1980s, now most numerous in British Columbia under the umbrella of Vela Microboard Association. In Ontario, see Aroha.
OAARSN	Ontario Adult Autism Research and Support Network	Website started in 2000 and Listservs with a focus on adults with ASD and creative supports for all who are vulnerable because of disability, providing information and communication for self-advocates, families, supporters and agency staff.
Occupancy Agreement		An agreement between an incorporated housing trust such as GSA and an individual with a developmental disability for the purpose of granting right of occupancy in property owned by the corporation.
ODSP	Ontario Disability Support Plan	Income support allowance paid to eligible adults with disabilities, who are unable to earn income from employment. Means-tested. Previously called FBA. Supposed to pay for rent, food, clothing and personal costs, but insufficient for appropriate housing for adults with high support needs.
Passport	Passport funding program	An Ontario direct funding program from 2006, for which eligible adults may apply to support community participation, notably in period of transition out of school.

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PATH	Planning Alternative Tomorrows with Hope	A group planning experience in which a vulnerable person, with family and friends, envisions elements of a good life and takes the first steps to realize their dreams.
PLAN™	Planned Lifetime Advocacy Networks	Innovative, family-directed organization dedicated to helping families create enduring personal networks around their loved ones with a disability.
PSA	Personal Support Agreement	Document detailing expectations for standard of personal care of a vulnerable person and the responsibilities of the person or agency providing such care. Appropriate when supports are individualized because of a person's complex and high support needs. Used by GSA to define roles and responsibilities in the agreement among the Person, the Aroha, Housing Trust and TPA.
SDMA	Supported Decision-Making Agreement	Tool for vulnerable person to express wishes to guide own support and care; an alternative to guardianship.
SDSC	Self-Directed Support Corporation	Generic name, especially in US jurisdictions, for entity to help person self-direct supports, similar to Aroha or microboard.
Self-directed planning		A process that recognizes the rights of a person with a disability to express their own dreams and needs for a good life and to decide how resources should be used to implement their plans. A stage beyond person-centred planning. Aka person-directed planning.

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SSAH	Special Services at Home	Government funding to individual disabled children and some adults (living in their family homes) for skills development and respite. May be administered by an agency or self-administered by family. A model (and modest) form of IF that, for adults, is to be merged with the Passport program.
S-T	Supported Typing	A form of AAC to help persons such as adults with autism who do not speak with their voices because of neuro-motor disorders to "type to talk". Formerly Facilitated Communicating.
TPA	Transfer Payment Agency	Incorporated entity recognized by MCSS as an agency to receive public funds, which may then be transferred to a person, family, or another organization.
Ulysses Clause	aka Ulysses Pact or Agreement	A freely made decision designed and intended to bind oneself in the future. The term is used in medicine, especially in reference to advance directives (aka living wills). May be chosen as part of SDMA by people who experience health fluctuations including times when they are unable to communicate in words.
Unencumb-ered		Independent and free of conflicts of interest. Used of the brokerage system of personal supports, which is separate and distinct from any agency providing direct services to clients.

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References

The GSA model offers some new and interrelated ways of helping adults with severe autism to have good whole lives. Each individual who lives with a unique combination of gifts and challenges can choose what adds up to a seamless and sustainable range of supports that is right for each person. While our own focus is on adults living with Autistic Disorder in Ontario, Canada, we have learned from various pioneering perspectives and projects by, with, and for people with any kind of disability. Here are references to some ideas and sources.

General background and context of ideas

Celebrating the Ordinary: the emergence of Options in Community Living as a thoughtful organization, by John O'Brien et al. (Inclusion Press and Options Community Living, 1998). See also other titles by O'Brien at www.Inclusion.com

Creating Good Life in Community: A Guide on Person-Directed Planning (2006) http://www.mcss.gov.on.ca/en/mcss/publications/developmentalServices/personDirectedPlanning/moreInfo.aspx Guide to resources on MCSS webpage.

A Good Life for you and your relative with a disability, by Al Etmanski (Planned Lifetime Advocacy Network, PLAN, 2000). See especially chapter 5, "Ensuring Choice," pp.178-225. Visit the www.PLAN.ca website

My Life, My Choice. Stories of struggles and successes with person directed living in a video illustrating the value of brokerage/facilitation in the lives of several adults supported by Windsor-Essex Brokerage for Personal Supports (Available from www.Inclusion.com, 2006).

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Pathways to Inclusion: Building a New Story with People and Communities, by John Lord and Peggy Hutchison (Captus Press, *2007).*
Visit http://www.johnlord.net/ and http://www.facilitationleadership.com

Stronger Together: ideas, reflections and suggestions about networks of support, by Bruce Kappel (Support & Trustee Advisory Services of Brampton Caledon, 1998).

Who Does What? The process of enabling people with learning difficulties to achieve what they need and want, by Steve Dowson (Values into Action, 1990, revised 1999). May be downloaded for private use only from http://members.shaw.ca/bsalisbury/wdw.pdf

GSA produced a video and printed record of proceedings of the conference organized in April 2005. ***Creative Supports for Vulnerable Citizens: Papers from the Guelph Spring Conference***, 80-page collection of presentations, with videotape summary of highlights, 49 minutes in VHS format, including:
John Lord on: "Creative Supports That Work: Values, Principles and Processes"; Judith Snow on "Building Supports with Individuals"; Barbara Leavitt on "From Housing to Creating My Home"; Peggy Hutchison on "Building Meaningful Supports for Work and Recreation Experiences"; Marlyn Shervill, Alice Quinlan and Michelle Friesen on "How Families and Communities Can Make Creative Options Work: The Windsor-Essex Experience".
See more at http://www.ont-autism.uoguelph.ca/CS-resources.html
The OAARSN website has an overview of Creative Supports at
http://www.ont-autism.uoguelph.ca/creative.shtml
See OAARSN What is Autism? webpage (including Autism in Adults) at
http://www.ont-autism.uoguelph.ca/autisminfo.shtml

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Listening to the Person

Communication issues and resources, including the value of Supported Typing for people who cannot speak with their voices, are surveyed in this DVD and book: ***Bridges-Over-Barriers: In Our Own Words***, book edited by Andrew Bloomfield, and DVD with same title produced with Christine Zorn, (Guelph Services for the Autistic for Bridges-Over-Barriers, 2010).
See more at http://www.ont-autism.uoguelph.ca/Bridges-announce-1.pdf

The Bridges-Over-Barriers webpage is at:
http://www.ont-autism.uoguelph.ca/bridges.shtml.
Communication rights are featured in Bridges-Over-Barriers Bulletin 3 (2007): http://www.ont-autism.uoguelph.ca/BoB-2007-3.pdf. Bridges bulletin 5 (2008) contains an article "Supported Decision-Making: listening to each one of us." http://www.ont-autism.uoguelph.ca/BoB-2008-5.pdf

Another new book that highlights transformative power of access to communication for adults who cannot use their own voices: ***Real People, Regular Lives: autism, communication & quality of life,*** by Sally R. Young (2011; order from the Institute on Disability Bookstore, University of New Hampshire).

On the Yukon model of a supported decision-making agreement, see the following and other links from it: http://www.hss.gov.yk.ca/decision_making.php
On Representation Agreements in BC see: http://www.nidus.ca/?page_id=50

Creating a Good Life in Community: a guide to person-directed planning (Plain language guide written for MCSS, 2006). May be read online or downloaded: http://www.mcss.gov.on.ca/documents/en/mcss/publications/developmental/GuideonPersondirectedPlanningFinal.pdf

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Internet Search Keywords: **supported typing, supported decision-making agreements** and **representation agreements**

Aroha Entities for Personal Support

The Microboard was invented and named by David Wetherow in Winnipeg in 1984, as a creative response to the movement of Manitobans out of long-stay institutions. For the Wetherows' brief history of microboard design and development: http://www.community-works.net/articles/microboard.htm. Entities called Microboards are most numerous in British Columbia where the Vela Microboard Association provides exchange of information and support for more than hundreds of individual Microboards. http://www.microboard.org The Wetherows and Vela have both consulted to people, families and organizations in the United States, Australia and Europe. The generic term "self-directed support corporation" is sometimes used in US jurisdictions.

The man around whom Ontario's first Aroha was incorporated has composed his own account of how his life has been transformed by his Aroha, self-expression using Supported Typing, homeownership and other interrelated strategies. ***Bridges over barriers in my life with autism*** by Andrew Bloomfield (Friends of Andrew Bloomfield and Guelph Services for the Autistic, 2011).

Internet Search Keywords: **microboard** (excluding the computer equipment), **aroha entities, self-directed support corporation**.

A Home of My Own

Canada's pioneers in designing a home around a person vulnerable through severe disabilities were probably the Schaefer family of Winnipeg. Nicola Schaefer described her daughter Catherine's journey to her own home by her mid-20s in a book and its sequel that have inspired many.

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Nicola Schaefer, ***Does She Know She's There?*** (Fitzhenry and Whiteside, 1978, revised edition 1999 including the sequel ***Yes She Knows She's There!***).

The Ouellette family of Windsor, Ontario created a home for their son David who lived there almost nine years before his sad death at the age of 36. His mother Alison wrote the story of how Dave's family organized the financial and physical aspects of the house and the management of personal supports.
Alison C. Ouellette, ***A Place Called Home: a story about a life unfolding*** (first published 2002, revised 2008. ISBN: 978-0-9733899-5-1). Copies may be bought from Windsor Essex Brokerage for Personal Supports at:
http://www.windsoressexbrokerage.com/

Only a few Ontario adults with developmental disabilities had achieved some form of individualized lives in their own home by 2007. During "transformation" consultations and discussions offered by the Ontario Ministry of Community and Social Services from 2003, it became clear that more families wanted this option. In mid-2007, the Ministry invited proposals for pilot projects as part of the Individualized Residential Model Initiative (IRMI). More than 60 projects were funded and 89 people were said by early 2009 to be living in an IRM that was "right for them". Ministry-hosted forums in April 2009 pooled reactions and recommendations from agencies and family members who had experience in working together in individualized residential projects. The summary report and appendices are available for reading online:
"A Home That's Right For Me" **Valuing Choice, Evolving Individualized Residential Options.** Summary Report of Policy Forums. Sponsored by the Ministry of Community and Social Services. (July 2009: Prepared by Jenny Carver & Associates). http://www.ont-autism.uoguelph.ca/IRM-2009-summaryreport.pdf
Appendices: http://www.ont-autism.uoguelph.ca/IRM-2009-Append.pdf

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Ten Steps to Realize a Personalized Plan

1.
Begin
Self-determination

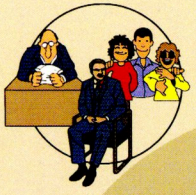
2.
Form Support
Cluster/Network

3.
Set Up Ways To
Understand And Make
Choices

4.
Make Personalized Plan
Using Maps And Paths

5.
Assess Ways And Means

6.
Weigh Up Options And
Decide Which Combination
Works Best



7.
Choose Broker To
Negotiate Supports And
Funding

8.
Choose Place To Live

9.
Set Up Quality Of Life

10.
Set Up Ways To
Co-Ordinate Everything